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Pepperdine University  
Graduate School of Education and Psychology

ABA IN NATIVE AMERICAN HOMES: A CULTURALLY RESPONSIVE  
TRAINING FOR PARAPROFESSIONALS

A clinical dissertation submitted in partial satisfaction  
of the requirements for the degree of  
Doctor of Psychology

by

Belinda Naomi Najera

January, 2012

Tomás Martinez, Ph.D. — Dissertation Chairperson

This clinical dissertation, written by

Belinda Naomi Najera

under the guidance of a Faculty Committee and approved by its members, has been submitted to and accepted by the Graduate Faculty in partial fulfillment of the requirements for the degree of

DOCTOR OF PSYCHOLOGY

Doctoral Committee:

Tomás Martinez, Ph.D., Chairperson

Shelley Harrell, Ph.D.

Bodil Sivertsen, Ph.D.

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## DEDICATION

I dedicate this scholarship to the indigenous people everywhere whom access  
their strength through beauty (oneness).

Hózhó jí, the blessing way

Hózhóogo naasháa doo  
Shitsiji' hózhóogo naasháa doo  
Shikéédée' hózhóogo naasháa doo  
Shideigi hózhóogo naasháa doo  
T'áá altso shinaagó hózhóogo naasháa doo

Házhó náhásdlíí  
Házhó náhásdlíí  
Házhó náhásdlíí  
Házhó náhásdlíí

In beauty I walk.  
With beauty before me I walk.  
With beauty behind me I walk.  
With beauty above me I walk.  
With beauty below me I walk.  
With beauty all around me I walk.  
With beauty within me I walk.

It is finished with beauty restored.  
It is finished with beauty restored.  
It is finished with beauty restored.  
It is finished with beauty restored.

-Navajo chant

## ACKNOWLEDGMENTS

I am sincerely grateful to my committee: Dr. Martinez, Dr. Sivertsen and Dr. Harrell. It has been an incredible honor to walk in the shadow of your greatness. Dr. Harrell, I am humbled by your wisdom, grace and kindness.

As the first in my family to have been granted the opportunity to go to college, I now know why so few first generation students actually complete the endeavor. The only way that this journey has been possible has been through the patience and understanding of my family. Mom, dad, Chrissy we are quite a team. Grandma Cleo gave me the gift of resilience. Strength can still be found simply by remembering her valuable indigenous teachings, bombast laugh and funny hairstyles. The mentorship provided by Dr. Sivertsen has pushed me more than any challenge I've faced to become a better professional and a better person. My dearest confidante and husband Michael, this is yet another accomplishment that would not have been possible without your love. Thank you Lux my love, you are light. I look forward to all that I will learn from witnessing your journey. I will always be your biggest fan.

Strong and amazing women have picked my chin up off the floor and dusted me off throughout this project. My love to Sarah Mc Cormack, Sawssan Ahmed, Gustina Woods, Olga Vasquez, Claire Lissone and lest I not omit the incredible community of mental health professionals, indigenous in blood and in spirit, dedicating themselves to their work within the Native communities. Grace, encouragement and hope were given freely with no repayment expected. I will carry these lessons always.

## VITA

Belinda Naomi Najera, M.A.

## EDUCATION:

2011 **DOCTOR OF CLINICAL PSYCHOLOGY,**  
Pepperdine University, Culver City, California.  
APA-accredited doctoral program in clinical psychology

07/2000 **MASTER'S DEGREE IN PSYCHOLOGY,**  
Pepperdine University, Culver City, California 3.95 GPA  
Graduate School of Psychology

06/1994 **BACALAUREATE IN PSYCHOLOGY,**  
University of California, Los Angeles  
with an emphasis in Behavioral Psychology,  
Center for the Behavioral Treatment of Children

---

## CLINICAL AND PROFESSIONAL EXPERIENCE:

**BEHAVIOR MANAGEMENT SPECIALIST,**

Provide one on one behavioral tutoring for children diagnosed with Pervasive Developmental Disorders and related disorders, utilize positive teaching and reinforcement techniques to increase desired target behavior while decreasing unwanted or inappropriate behavior, work with a variety of specialists, care givers and educators, develop individualized programs suitable for the cognitive and social advancement of the client, 05/96-present

Saint John's Medical Hospital-Child and Family Dev. Center

**Clinical Psychology Intern, APA accredited**

Provide individual and family therapy for children and adolescents in a community mental-health setting. Administering cognitive and psychological assessment measures including: Woodcock- Woodcock-Muñoz Language Survey, English Ed (WMLS-English), Normative Update, Woodcock-Muñoz Language Survey, Spanish Ed (WMLS-Spanish), Normative Update, Wechsler series of intelligence tests (WPPSI, WISC-III & IV, WAIS-III), Wechsler Individual Achievement Test-2<sup>nd</sup> Edition (WIAT), Vineland Adaptive Behavior Scales (Interview Edition, Expanded Form), Behavior Assessment System for Children-2<sup>nd</sup> Edition (BASC-2): Self-Report of Personality (SRP) and Parent Rating Scale (PRS), Projective Drawings (Draw a Person, House, Family, Tree, Person in the Rain), Robert's Apperception Test for Children (RATC), Rorschach Ink Blot Test, Sentence Completion, Thematic Apperception Test (TAT), Trauma Symptom Checklist for Children (TSCC), Bender-Gestalt Test of Visual-Motor Integration, Beery Developmental Test of Visual-Motor Integration (VMI), Expressive One- Word Picture Vocabulary Test, 2000 Edition (EOWPVT), Receptive One- Word Picture Vocabulary Test, 2000 Edition (ROWPVT), Universal Nonverbal Intelligence Test (UNIT), Conner's

Parent Rating Scale-Revised, Long Version, Achenbach Child Behavior Checklist (CBCL-Parent), Children's Depression Inventory (CDI), Psycho-social chart review, clinical interviews, attend weekly Psycho-social team meetings, 09/05–03/06

Mount Saint Mary's College—Counseling & Psychological Services

### **3<sup>rd</sup> YEAR DOCTORAL PRACTICUM**

Supervisor: Carrie Jo Johnson, Ph.D., Doctor of Psychology

Foster personal development by offering a variety of programs to address undergraduate and graduate student concerns. Provide individual therapy, couples counseling, and crisis intervention to resolve personal issues, present psycho-education programs on issues related to the stressors associated with college life, 08/04–07/05

The City of Hope Medical Center, Division of Pediatrics, Neuropsychology Program

### **2<sup>nd</sup> YEAR DOCTORAL PRACTICUM**

Supervisor: Sunita Patel, Ph.D., Doctor of Psychology

Administration of a variety of assessment measures to children and with cancer and adult survivors of cancer. Assessment tools include: Wechsler series of intelligence tests (WPPSI, WISC-III & IV, WAIS-III), Vineland Adaptive Behavior Scales (Interview Edition, Expanded Form), McCarthy Scales, Wide Range Achievement Test (WRAT-III), Wechsler Memory Scale-Third Edition (WMS), Children's Memory Scale (CMS), Beery Developmental Test of Visual-Motor Integration (VMI), California Verbal Learning Test (CVLT), Trail Making Test A & B, Controlled Oral Word Association (FAS) & Animals, Grooved Pegboard, Conner's Parent Rating Scale-Revised, Long Version, Achenbach Child Behavior Checklist (CBCL-Parent), Beck Depression Inventory (BDI), Children's Depression Inventory (CDI), Wide Range Assessment of Memory and Learning (WRAML), Medical and Psycho-social chart review, clinical interviews, attend weekly Psycho-social team meetings, 10/03–08/04

Seeds University Elementary School, UCLA

### **1<sup>st</sup> YEAR DOCTORAL PRACTICUM**

Supervisor: Jeffrey Jacobs, Ph.D.,

Client intake reports, case management, individual psychotherapy, group counseling, crisis intervention, administration of the Woodcock Johnson, classroom observations, behavioral analysis, coordination of therapeutic interventions with the individual teaching staff, 09/02–06/03

San Fernando Child Guidance Clinic, Northpoint Day Treatment

### **MENTAL HEALTH REHABILITATION SPECIALIST**

Created and maintained behavioral programs for individual clients in a multidisciplinary classroom setting, monitored and recorded half-hour as well as daily progress reports, assisted in consistent follow through of interventions, organized positive reinforcement schedules, participated in team case management meetings, 09/95–09/96

Center for Autism and Related Disorders, Encino

**BEHAVIORAL SPECIALIST**

Senior Therapist, performed two-day workshop presentations on behavioral intervention programs on childhood autism for parents and professionals throughout the United States, organization and maintenance of behavioral log books assessing progress toward projected I.E.P. goals, behavioral assessments, school site visits and consultations for teaching staff, instruction and training for parents and behavioral staff, 11/94–09/95

Atwater Park Center, Atwater Park

**BEHAVIORAL PROGRAM CONSULTANT**

Created positive behavior management programs for preschool children and infants with developmental disabilities, compiled a positive behavior management reference manual to be utilized by the school staff, recorded data on behavior progress both at the school and in the home, consulted with multidisciplinary specialists and physicians to develop an appropriate program for the child, attended regular trainings and workshops provided by the Head Start organization, 03/94–06/95

University of California, Los Angeles,

**BEHAVIORAL SPECIALIST**

Under the supervision of Ivar Lovaas, Ph.D., provided behavior therapy for the treatment of childhood autism, collected and recorded behavioral progress data, as a Senior Therapist trained new therapists and conducted performance appraisals, scheduled personnel, organized and led clinic meetings, assisted with longitudinal research on the effects of intensive behavioral intervention on children diagnosed early with autism, 03/92–12/94

**CONTINUING EDUCATION AND CLINICAL TRAINING:**

- 2010 Indian Health Services/ Bureau of Indian Affairs Behavioral Health Conference, *A Shared Vision: Past, Present, and Future*. Sacramento, CA
- 2008 *Cross-Cultural Skills in Indian Child Welfare*, National Indian Child Welfare Association, Portland, OR
- 2006 *Positive Indian Parenting: Honoring our children by honoring our traditions*, National Indian Child Welfare Association, Portland, OR
- 2005 23<sup>rd</sup> Annual “*Protecting Our Children*” *National American Indian Conference on child Abuse and Neglect*, National Indian Child Welfare Association, Albuquerque, NM
- 2005 *Reaping What We’ve Sown, Coalescing our Knowledge about Health, Development, and Multiculturalism*, California Psychological Association’s 59<sup>th</sup> Annual Convention, Pasadena, CA
- 2004 Zero to Three Annual Conference, *Sharing a Vision for young children and families*, 19<sup>th</sup> National Training Institute, Sacramento, CA
- 2004 *Healing American Indian Nations*, The American Indian Health and Wellness Conference, Los Angeles County Department of Mental Health, Los Angeles, CA

- 2004 *Does Culture Matter in the Mental Health of Latino Youth?*  
Antonio Polo, Ph.D., Colloquium sponsored by Pepperdine University, GSEP
- 2004 *Association for Pediatric/Oncology Nurse's Foundations of Pediatric Hematology/Oncology: A comprehensive orientation and review 3-day course*, sponsored by City of Hope Medical Center, Miller Children's Hospital, Long Beach, Children's Hospital of Orange County, Children's Hospital of Los Angeles, University of California Los Angeles
- 2004 *Parent-Adolescent Communication and Adolescent Adjustment in Latino Families*, Rosalie Corona, Ph.D.  
Colloquium sponsored by Pepperdine University, GSEP
- 2003 *The Making of a Therapist: A Practical Guide for the Inner Journey*, Louis Cozolino, Ph.D., Colloquium sponsored by Pepperdine University, GSEP
- 2003 *Psychologists Training Physicians: Providing Culturally Responsive Care to Latino Populations*, Luis Guevara, Psy.D., Colloquium sponsored by Pepperdine University, GSEP
- 2003 *Understanding Latino Cultural Beliefs About Health and Illness*, Sandra Rivera, Ph.D., Colloquium sponsored by Pepperdine University, GSEP
- 2003 *Narrative Therapy*, Duncan Wigg, Ph.D., Director: Pepperdine Community Counseling Center, Colloquium sponsored by Pepperdine University, GSEP
- 2003 *Seven Habits of Highly Ineffective Couples...and How to Help Them*, Dennis Lowe, Ph.D., Director: Center for the Family and Emily Scott-Lowe, Ph.D., Colloquium sponsored by Pepperdine University, GSEP
- 2002 *The Neuroscience of Psychotherapy*, Lou Cozolino, Ph.D.  
Colloquium sponsored by Pepperdine University, GSEP
- 2001 Zero to Three Annual Conference, 16<sup>th</sup> National Training Institute: *Meeting the needs of infant, toddlers and families*, San Diego, CA

#### PRESENTATIONS AND PUBLICATIONS:

Najera, B. N., (2004, November). *Becoming a Psychologist*. Presented at Mount Saint Mary's College-Doheny Campus for students enrolled in a Health Sciences class. Los Angeles, California.

Najera, B. N., (2004, November). *The Application of Cognitive Behavioral Approaches to Children and Adolescents with Asperger's Disorder and Comorbid Depression*. Presented at Graduate School of Psychology and Education for a Master's level course on treatment methods in psychotherapy. Culver City, California

Najera, B. N., (2004, October). *Making Peace with Your Body: An overview of eating problems and self-esteem*. Presented at Mount Saint Mary's College-Doheny Campus for all interested students. Los Angeles, California.

Najera, B. N., (2004, September). *Doctoral Roundtable: Are you interested in applying for a Doctoral degree in Psychology?* Presented at Pepperdine University, Culver City Campus for all interested students. Culver City, California.

Patel, S.K., Beaumeister, B. Katz, E., Turk, A.A., Najera, B.N., & Buckwater, J.G. (June 2004). Parent Behaviors and Cognitive Outcomes Among Childhood Cancer Survivors, Poster presented at the Annual Meeting of the American Academy of Clinical Neuropsychology, Minneapolis, Minnesota.

Glover, D., Liener, W., Lillas, C., Najera, B., & Price, S. (2001 December). Interdisciplinary Infant mental Health Training Program, Cedars-Sinai Medical Center-Early Childhood Center, Poster session presented at the Zero to Three Annual Conference 2001 in San Diego, CA.

Baltaxe, C, Cantwell, E, Crecelius, G., Davanzo, P., Kleiner, J., Mc Cracken, J., & Najera, B. (2001). Cognitive changes during topiramate therapy. *Journal of the American Academy of Child and Adolescent Psychiatry*, 40(3), 262-263.

Atienza, J., Belin, T., Davanzo, P., Faull, K., Gunderson, Mc Cracken, J., & Najera, B. (2000 October). Intracellular calcium in childhood mood disorders. Poster session presented at the American Academy of Child and Adolescent Psychiatry annual meeting, New York, NY.

Gibson, J. & Najera, B. (2000 March). The effect of smiling on the perception of an individual's attractiveness and intelligence. Paper presented at the California Psychological Association annual meeting, San Jose, CA.

#### LECTURES:

- |          |  |
|----------|--|
| 12/01/10 | <i>Intervention Strategies for Autistic Disorders</i><br>Pepperdine University, GSEP; Dr. Carol Falender   |
| 11/19/09 | <i>Pervasive Developmental Disorders</i><br>Pepperdine University, GSEP; Dr. Carol Falender  |
| 06/12/08 | <i>The Treatment of High Functioning Autism and Asperger's Syndrome</i> Pepperdine University GSEP; Dr. Jena Kravitz   |
| 05/22/08 | <i>The Treatment of High Functioning Autism and Asperger's Syndrome</i> Pepperdine University, GSEP; Dr. Carol Falender  |
| 04/02/08 | <i>The Treatment of High Functioning Autism and Asperger's Syndrome at the Post Secondary level</i> , Mount St. Mary's College, Chalom Campus; Dr. Susan Salem |
| 06/14/05 | <i>Applying Cognitive Therapy techniques when working with Children</i> , Pepperdine University, GSEP; Dr. Sepida Sazgar                                       |

## ABSTRACT

This project attempts to create a dialogue about respectful service delivery to Native American families with a child diagnosed with an Autism Spectrum Disorder (ASD). Improving interactions between professionals and Native American families can not only advance the ASD child's cognitive and behavioral gains, but also respectfully honors the beliefs of the caregivers. A systematic search of pertinent peer-reviewed empirical sources in the areas of Autism, paraprofessional training, and multicultural psychology was conducted to develop a training resource for paraprofessionals providing home based ABA tutoring. The completed resource is comprised of three training modules, which are intended to be presented over the course of three days of instruction and lead by a licensed mental health professional. Licensed mental health clinicians acting, as ABA program coordinators would be responsible to utilize this training as an addendum to current, readily available ABA training manuals. An expert panel of licensed mental health professionals working with the Native American ASD population evaluated this training resource. Results: The three members of the expert panel found that despite the need to further develop group discussion topics and to include additional examples related to Native American caregiver perceptions of this style of treatment, the resource has potential for use in preparing paraprofessionals for ABA tutoring in Native American homes.



## **Chapter 1: Introduction**

In the United States, it is estimated that approximately one in 110 children are classified as presenting with an Autism Spectrum Disorder (ASD; Centers for Disease Control and Prevention [CDC], 2009). The ASDs are a group of developmental disabilities defined by marked social impairment that can range in severity from mild to acute (American Psychiatric Association [APA], 2000). Impairment includes a triad of characteristics including disruption in the ability to interact socially, impaired social communication, and restricted and or repetitive behaviors or interests (APA, 2000; Wing, Gould, & Gillberg, 2011).

Within the field of psychology, Euro-American mental health treatment approaches have been adapted to fit the rest of the North American populous, including marginalized populations (Huey & Polo, 2008). When working with these populations, clinicians are ethically bound to take measures to ensure ethical treatment. These actions include using appropriate language and educating themselves about their clients' culture of origin to ensure culturally relevant treatment (APA, 2000). A number of peer-reviewed articles have been published in the topic area of cultural competency. They highlight the ways in which the differential of power held by individuals in helping professions are further complicated when these professionals engage in work with individuals from a culture different than their own (Cole, 2008; McGoldrick, Giordano, & Garcia-Preto, 2005; Rogers-Sirin & Sirin, 2009; Summers & Jones, 2004). These professionals have chosen their career with the goal to utilize their knowledge to assist their clients in crisis. In order to provide proficient treatment, a clinician must establish rapport, making

cultural competency of paramount importance. Professionals with the best intentions of providing culturally sensitive treatment for clients from a different cultural background can find themselves struggling to establish a rapport and meet their clients' individual needs (Cole, 2008).

The first and most important step toward providing culturally relevant treatment must begin with therapists making an effort to develop a clear understanding of their own cultural identity (McGoldrick, Giordano, & Garcia-Preto, 2005). Besides having the professional responsibility to be culturally competent, mental health practitioners have the added challenge of working with a variety of counseling theories and approaches that have not necessarily been developed with an individual's culture, gender and/or sexual orientation as a primary focus (Gallardo, Johnson, Parham, & Carter, 2009; LaFromboise & Rowe, 1983). Today, although efforts have been made to provide culturally responsive treatments for diverse populations, many of the existing approaches continue to lack adequate research to support their efficacy (Huey & Polo, 2008).

Empirical research supporting these theories has been conducted with participants that either identify with this more Eurocentric worldview or measured using Eurocentric standards as the norm. Culturally competent counselors must take responsibility for the limitations present in their chosen counseling approach and supplement their theoretical knowledge base with information that will enable them to best serve their clients (Gallardo et al., 2009). As outlined by the DSM-IV-TR, when developing a cultural formulation, a clinician will consider the client's culture or origin, level of identification with that culture, how their cultural context influences how distress and troubling symptoms are expressed, and how the therapeutic relationship may be affected by their

cultural differences (APA, 2000). The training of culturally competent therapists generally holds that clinicians must be aware of their own ethnic identities and strive to understand and respect the value system of their clients (McGoldrick et al., 2005). In the field of developmental disability, this balance is further complicated by the frequent use of paraprofessionals. Paraprofessionals whom work as behavioral tutors with individuals diagnosed with a developmental disability are not required to possess proficiency in cultural issues of any form. To complicate matters, these individuals are commonly referred to as “behavioral therapists” although they are not licensed therapists and many possess a minimum of a high school degree. Without receiving the education of a therapist, these paraprofessional tutors are expected to conduct behavioral services on their own in the client’s home. Supervision of these paraprofessionals generally consists of one hour, monthly team meetings and occasional observation by a behavioral tutor whom possesses more experience in the field.

Identification with a particular culture indicates that one can hold a set of values that differs drastically from the mainstream Euro-American culture of North America (McGoldrick et al., 2005; Zions, Zions, Harrison, & Bellinger, 2003). The belief system provides schemas for gender roles and educating children that will further enforce the values held by the identified group. The aspiration is for mental health treatment providers to improve their treatment efficacy by respectfully working within the realm of their client’s cultural context (Lo & Chung, 2005). Clinicians can communicate their genuine desire to appreciate their clients’ experience by making an effort to recognize the impact that racism and discrimination have on the clients’ lives (Zions et al., 2003). A clinician’s failure to take into consideration culture specific discrimination such as the

lasting effect of a history of oppression would be doing a disservice to their minority clients (Gone, 2009). A client whose ancestors suffered at the hands of the dominant culture can be extremely distrustful of any professional who appears to be supporting the values of the dominant society (Klonoff & Ladrine, 1997). This can potentially prevent effective rapport building and treatment (Gone, 2009).

Research has supported that African Americans continue to receive inferior mental health care as compared to Euro-American patients (Mandell & Novak, 2005; Zionts et al., 2003). Byng (1998) explained that African American Muslim women possess a multidimensional foundation for discrimination exposing them to frequent mistreatment. The accumulative impact of regular acts of discrimination can have debilitating effects on an individual's self-worth and have been argued to result in the synthesis of a collective memory of mistreatment and oppression shared by the community (Byng, 1998). In addition to the aforementioned factors, the added burden of poverty common in marginalized groups such as rural American Indian populations, contributes to additional disparities in mental health care utilization when it is most needed (Walkup et al., 2009; Yurkovich & Lattergrass, 2008).

### **Statement of Problem**

Current training for Adaptive Behavioral Analysis (ABA) tutors excludes preparation for working in a culturally responsive manner and this is essential when working with the Native American population (Walkup et al., 2009; Zionts et al., 2003). ABA training also excludes preparing paraprofessional tutors for providing behavioral services in the very personal and culturally laden confines of the client's home. Although ABA training manuals are readily available at most bookstore chains, these books have

not yet addressed the additional skills required for paraprofessionals to work with individuals from another culture. Without special attention to cultural issues, paraprofessionals may not be able to gain entry into the home leading to program non-compliance or higher attrition rates.

### **Purpose of the Study**

The purpose of this study is to develop a culturally responsive training resource to be used by licensed ABA program directors to prepare their teams of paraprofessionals to conduct ABA services in Native American homes. Current training provides adequate preparation on the principles of ABA; however, it is imperative that additional training in which stress is placed on the importance of cultural competence skills be included in this training.

### **Literature Review**

**Native American mental health services—Overview.** In 2001, according to Indian Health Services (IHS), a branch of the U.S. Public Health Service responsible for mental health services in Indian country, there were two psychiatrists and four psychologists per 100,000 Native American individuals versus the availability of 14 psychiatrists and 28 psychologists available to serve 100,000 in the general U. S. population (Gone, 2004). To make matters worse, the Native American population experiences a greater frequency of depression, suicide, substance abuse, poverty, unemployment, and mortality, as compared to other ethnic populations in the United States (U.S. Bureau of the Census, 2002). Mental health services are reported to be under-utilized by Native American clients and for those who do seek assistance. Native Americans have one of the highest treatment dropout rates among ethnic minorities

(LaFromboise, 1988; Rhoades, 2003). The history of mistreatment by early European colonizers and the turbulent beginning of Native American health services continues to pose difficulties for both service providers and clients, resulting in service underutilization (Belcourt-Dittloff & Stewart, 2000). Given the population's historical socio-demographic experience, which includes broken treaties, poverty, forced relocation, physical and emotional punishment for expressing cultural identity, and prejudice, it is unsurprising that Native Americans would be hesitant and distrustful toward the dominant culture and what is perceived as Eurocentric health care (Walkup et al., 2009).

**Current theoretical models for treatment in the Native American community.** A majority of the empirical literature on Native American mental health treatment and services focuses on substance abuse. Mental health issues are discussed as being comorbid to problems of substance abuse with only minor references to developmental disabilities such as ASD (Gone & Alcántara, 2007; Jackson & Hodge, 2010). In response to the rate of underutilization of counseling services, Bichsel and Mallinckrodt (2001) found that Native American women living on a reservation in Oregon preferred interacting with an ethnically similar female counselor who used a non-directive counseling style. Native American women who indicated a stronger identification with traditional beliefs were found to prefer the culturally sensitive Anglo counselor as opposed to the Native American counselor who did not exhibit a culturally sensitive approach.

Gone and Alcántara (2007) reviewed scholarly publications on evidence-based treatment and prevention for American Indians and Alaska Natives. The researchers

found that out of 56 articles and book chapters, only two studies presented an adequate sample size, focused on prevention, and were quasi-experimental, as their control groups were created under the constraints of recruiting only a subset of individuals at random to the wait-list control group or requiring pre-treatment matching on a mental health variable (depression) to make the experimental and control group similar. The researchers emphasized that, despite decades of research literature, only two viable studies existed: the prevention of depression in older (+45) individuals and the prevention of suicide in adolescents.

In both studies the focus was on preventative approaches to substance abuse. In this study the paucity of research on the effectiveness of traditional Native American ceremonies and healing techniques was also noted. To make matters more complex, information on the prevalence of mental illness is said to be comparable to that of the general American population with the exception of substance abuse, which is more prevalent among Native Americans. This is meant to account for the fact that such diagnoses are based on Eurocentric values and theories of mental illness. The studies utilized psychometric tests and screening tools that do not provide norms for the Native American population (Rieckmann, Wadsworth, & Deyhle, 2004; Summers & Jones, 2004).

### **Traditional Native American Values**

There are approximately 5.2 million individuals who identify themselves as Native American in the United States (U. S. Census Bureau of the Census, 2011). Out of this population, there are currently 336 federally recognized tribes that are eligible for funding through the United States Bureau of Indian Affairs, and among them there exists

about 250 different languages and dialects (U. S. Bureau of the Census, 2002; McCarty, 2008). Within each of these tribes or bands, a variety of norms and mores exist. Each group possesses their own values as well as varying degrees of cultural identification and assimilation to general American culture. Despite the diversity across tribes, the two important themes that emerge are the importance of familial relations and spirituality. For the purpose of this scholarship, the general values of North American Native people will be presented; however, it is important to stress that further research into individual customs would be necessary when a specific tribe is identified.

**Native American worldview.** Traditional Native Americans possesses a relational worldview that emphasizes how all things are interrelated. This view values harmony with the natural and spiritual world along with a philosophy emphasizing humility and sharing as opposed to competitiveness (McGoldrick et al., 2005; Red Horse, 1997). This philosophy values the act of placing community needs before individual needs (Guillory & Wolverton, 2008). A great deal of respect is bestowed on elders of the group who are responsible for teaching and carrying out the traditional customs. There is a time orientation that favors living in the present and in which it is acknowledged that events will occur in their own time, that is, an event will end when it is finished and not according to a present schedule. This view of time is in opposition to the mainstream view, in which being an agent of one's time, making actions happen at one's own will, and living toward the future are valued. As opposed to seeking scientific justification, a traditional Native American worldview favors understanding phenomena in terms of the supernatural. It is clear the ways in which this worldview is at times in direct opposition to the Western world view which values freedom, physical health and enterprise.



**Native American families.** Native American's family relations are so important that, traditionally, when individuals meet for the first time, they describe themselves in terms of whose family they belong to and by the location they come from. This relationship with one's family and ancestors is of utmost importance and is considered to be interrelated like a circle with the earth and other forces of nature (Garrett & Garrett, 1994).

Native American families that choose to follow the traditional lifestyle of generations past favor grandparents as the primary caregivers of children (Bahr, 1994; Mutchler, Baker, & Lee, 2007). Child rearing is the main responsibility of a child's grandparents, in contrast to Western standards, which places the responsibility on the birth parents (Herring, 1990). While grandparents watch over the children, more traditional Native American birth parents are responsible for all economic provisions (Garrett & Garrett, 1994). It is not uncommon for more traditional households to house both the nuclear and extended family (Guillory & Wolverton, 2008). An ABA tutor who is not aware of these alternative family roles and structure could have the impression that the birth parents of the client are negligent of the care for their children. Tutors may also undervalue the importance of including elder members in the behavioral program or may even fail to acknowledge them respectfully when entering the home. This kind of cultural violation can be deeply offensive to the family and result in decreased compliance or program support.

One of the strongest-held values by Native Americans across tribes and bands is that of the importance of family. Although there can be great diversity of beliefs across tribes such as those regarding family structure, for example, matriarchal versus

patriarchal rule, the core value of the importance of family is universal in a traditional Native American household (Garrett & Garrett, 1994; Red Horse, 1997). Family is defined as one's blood relatives, which includes all extended family. When a traditional Native American refers to their family, they include grandparents, aunts, uncles, and cousins. However kinship is not limited by blood relatedness. Cousins are referred to as siblings and terminology does not exist to distinguish relations by marriage, such as in-laws; these individuals are simply considered to be a part of the family. Important members of the community can also be acquired into the family. This is especially true with reference to healers or medicine people. In other words, one's social or cultural relationship to the family can be the defining element in one's relatedness.

The concept of family relatedness extends to include other's relatedness to the tribe as well. Animals are referred to as "four-legged brothers and sisters", the earth as "our Mother", Father Sky", "Grandmother Moon," and "Grandfather Sun" (Garrett & Garrett, 1994)." This emphasizes one's interrelatedness with the universe to be both biological and spiritual (Garrett & Garrett, 1994; Portman & Garret, 2006).

### **Native American Spirituality**

Traditional spiritual beliefs emphasize a circular relationship in which one must maintain harmony and balance within oneself as well as with nature and the spirit world to experience spiritual wellness. An emphasis is placed on making choices that benefit the greater community over choices that further independent wealth. The metaphor used to promote spiritual beliefs in harmony is the circle. The circularity of life is utilized in various ceremonies to emphasize that life is a cycle that continues and begins again. Behavior that one engages in now will affect many more generations to come.

The medicine wheel is a circle, which is divided into quadrants symbolizing the four sacred directions. The four directions, which are at times depicted in the colors red, black, white, and yellow; symbolize the spiritual elements of fire, earth, water, and wind. The sacred elements are considered gifts bestowed by the creator that are to be respected. The quadrants are also used to symbolize the four dimensions of a person: (a) spiritual, (b) emotional, (c) physical, and (d) cognitive. Unlike the Western conceptualization of an interaction between one's mind and body, the Native American medicine wheel includes all four indivisible quadrants. One's spirituality and physical elements which are of equal importance to one's mind and body. Individual harmony can be achieved when one finds a balance among their emotional, spiritual, physical and mental health.

Yurkovich and Lattergrass (2008) conducted a study which examined how "good health" versus poor health is defined by Native Americans suffering from persistent mental illnesses. Participants described an unhealthy state as one in which a person loses the ability to keep the four quadrants balanced. When an individual experiences active mental illness, they have an imbalance of harmony; that is, they are experiencing suicidal ideation (cognitive), depression, or feelings of rage (emotion), loss of hope in one's support (spiritual) and poor health due to poor diet (physical; Portman & Garrett, 2006). A healthy state is defined as equilibrium of the four domains of the medicine wheel (Portman & Garrett, 2006).

It is important to note that these aforementioned values are traditional Native American beliefs. Great variability exists amongst the population that identifies themselves as Native American. One's cultural beliefs are a synthesis of internal and

external processes. One must take into account not only variation between tribes but also varying levels of acculturation of the client.

### **Native American Perception of Developmental Disability**

Given the number and diversity of Native American tribes, specific traditional beliefs about disability vary. A disability can be understood as a gift or punishment from the Creator (McCallion, Janicki, & Grant-Griffin, 1997; Joe, 1997; Patterson, 1997).

### **Native American Identity Then and Now**

An individual's cultural identity is a personal choice and all individuals lie on a continuum of identification within their particular community. An individual's degree of genetic relatedness, or "Indian bloodline", tends to be the accepted means of identifying an individual as being Native American; however, this is simply the beginning of determining how a person identifies with a group. Two individuals with the same genetic level of relatedness to a Native American bloodline could differ greatly in their preferences, particularly if one lacks exposure to Native American cultural events versus an individual born on a reservation and raised speaking the native tongue (McGoldrick et al., 2005). Many contemporary Native Americans have described themselves as living in "two worlds", which includes varying degrees of commitment to the Native American as well as the mainstream American worldview (Guillory & Wolverton, 2008). Once an individual's level of cultural identity is assessed, their exposure to and understanding of the contentious relationship between Native Americans and the colonization process needs to be understood.

## **Cultural Strength Versus a Deficit Orientation to Treatment**

When early colonial settlers described the Native American way of life as barbaric, advocates for Native Americans created policies for their protection, however these policies took the tone of civilizing the uncivilized or, “taking the savage out of the Indian” (Bee & Gingerich, 1977; Gone, 2004; McGoldrick et al., 2005). This deficit-focused approach has dominated most of the treatment approaches developed specifically for Native Americans. Given the atrocious historical trauma, high rates of mortality, substance and physical abuse, it is imperative for mental health practitioners to better understand the Native American client in context. Special consideration must be given to the fact that the client and their family lineage has had the strength to have survived for generations since the arrival of early colonizers. Much of this resilience can be derived from their rich cultural beliefs. The intended purpose of the *ABA in Native American Homes* is not only to inform paraprofessionals about the history and special concerns related to this client, but also to emphasize and build upon the abundant strengths inherent in traditional Native American beliefs. These individuals are not to be approached as victims, but as survivors.

The search for empirically supported culturally relevant mental health services for the postcolonial indigenous people of North America continues. Empirically tested treatment modalities have been developed specifically for the treatment of substance use and abuse in Native American populations; however, there is a paucity of research on the treatment of symptoms associated with other mental health concerns. Treatment providers dedicated to serving Native Americans must routinely weigh the ideological effects of their interventions while ensuring that their clients can retain the parts of their

culture that offer them strength and resiliency (Gone, 2009). One's clinical training can offer this preparation and begin this dialogue, however currently paraprofessionals may not be entering the client's life equipped with this skill.

**Cultural competence.** Mental health specialists are ethically responsible for delivering culturally competent support to their clients. This requires clinicians to attain a level of appreciation for their clients' value systems, beliefs, and customs. According to LaFromboise, Coleman, & Gerton (1993), if one assumes that culture is shaped and influenced by one's cognitions and responses in a particular social environment, to achieve cultural competence, one must

(a) possess a strong personal identity, (b) have knowledge of and facility with the beliefs and values of the culture, (c) display sensitivity to the affective processes of the culture, (d) communicate clearly in the language of the given cultural group, (e) perform socially sanctioned behavior, (f) maintain active social relations within the cultural group, and (g) negotiate the institutional structures of that culture. (p. 396)

Without this effort to improve one's understanding of a client's cultural context, establishing rapport and even simple communication can be thwarted. Still worse, the client may experience the clinician as naïve or disrespectful and the treatment as destructive with regard to their cultural beliefs (Jackson & Hodge, 2010; LaFromboise & Rowe, 1983; Yukovich & Lattergrass, 2008). Research supports that providing culturally appropriate services can improve attrition and treatment outcome (Hays, 2009; Jackson & Hodge, 2010; LaFromboise & Rowe, 1983).

As there are countless possible variations in culture and degree of acculturation within the dominant culture, professionals must first examine their own beliefs and values before building a skill set to work with an individual who identifies with a different culture. Achieving cultural competency requires an ongoing desire to deeply

understand a culture. Such exploration covers many domains and the process of acquiring such skills can be life-long (LaFromboise et al., 1993). A single course on the subject in a clinician's training could not be sufficient to cover such self-examination and careful regard for another (Rogers-Sirin & Sirin, 2009). One must commit to ongoing self-assessment and genuine interest in better understanding others.

**Bicultural competence.** Bicultural competence refers to instances in which an individual is capable of successfully navigating social situations involving two different cultures. One must be able to present appropriate social behavior and decorum while maintaining equal respect for both cultures. Not only does bicultural competence involve having an accurate understanding of the two relevant cultures, but it also involves the ability to discriminate when it is appropriate to invoke specific behaviors expected in the proper context (LaFromboise & Rowe, 1983). Native Americans are indigenous, in contrast to immigrants to the United States; therefore, their existence is often described as straddling two worlds; that of their traditional Native American ancestors and that of the dominant colonial society.

### **The Culture of Providing In-Home Services**

**Entry into Native American homes.** Although behavioral approaches can be theorized as being culture free, home-based treatment presents a host of issues that paraprofessionals must be prepared to encounter. A client's home may expose a paraprofessional to a plethora of factors that they may not have expected to be a part of their job. Standard training of paraprofessionals to conduct ABA includes the basic principles of behavioral therapy as well as behavioral rationale for the treatment approach. However the job is not as simple as walking into a house, sitting with a child,

and beginning a pre-prepared behavioral program. Paraprofessionals will find themselves exposed to the clients' lifestyles, the resources available to them, their religious and political affiliations, and possible family chaos and/or marital discord (Schacht, Tafoya, & Mirabla, 1989). With so many factors at play, the service provider will need to be able to tolerate experiencing moments when they are not in complete control of the therapy environment (Schacht et al., 1989).

### **Overview of the Autism Spectrum Disorders Diagnostic Criteria**

The Pervasive Developmental disorders are psychiatric impairments with childhood onset that span throughout an individual's lifetime. The term Pervasive Developmental disorders includes five diagnostic sub-categories: (a) autistic disorder, (b) childhood degenerative disorder, (c) Asperger's disorder, (d) Rett's syndrome, and (e) pervasive developmental disorder not otherwise specified (Buitelaar, Van der Gaag, Klin, & Volkmar, 1999; Szatmari, 2000; Wing & Gould, 1979). In anticipation of the 2013 publication of a new edition of the *Diagnostic and Statistical Manual*, it has been proposed that the diagnosis of Asperger's disorder will be subsumed into the Autistic disorder category.

Autism is a mental disorder that is classified as a pervasive developmental disorder (APA, 2000). Hans Asperger and Leo Kanner separately identified children with similar symptom profiles. In 1943, two separate papers were published in which children presenting with characteristics such as being withdrawn into their own world, delayed or echolalic speech, and an obsessive desire to maintain sameness in their life were described. Leo Kanner, a self-taught pediatric psychiatrist, described 11 children as possessing "autistic disturbances of affective contact," which was later referred to as



early infantile autism (Kanner, 1943). Diagnosis was found to typically occur in early childhood when the caregiver or pediatrician became concerned about the child's delay in reaching developmental milestones such as a paucity of babbling or speaking and aloof behavior related to the absence of eye contact.

Autism is a pervasive developmental disability, classified in the *Diagnostic and Statistical Manual IV-TR*, which tends to be diagnosed after age two (APA, 2000). Based on personal experience following 19 years, working with individuals diagnosed with an ASD, referrals for diagnosis tend to occur at this age as parents notice not only that their child has not reached developmental milestones for language, but parents also note under developed social skills as compared to toddlers of similar age. Caregivers can begin to recognize that their child does not attempt to share their experiences of novel stimuli by motioning or pointing. These toddlers do not bring items they find interesting to share with their parent or caregiver. Autism impacts development in the areas of social and communication ability (APA, 2000). Children with an ASD characteristically exhibit impaired reciprocal interaction and communication skills along with the presence of repetitive or stereotyped behavior and interests (APA, 2000). According to the Centers for Disease Control and Prevention, approximately 34 in 10,000 children ages three to 10 years of age have a form of ASD (CDC, 2004).

**Overview of Autism Spectrum Disorder.** The Autism spectrum disorders are a well publicized, although not necessarily well understood developmental impairment. The spectrum includes a range of functioning that begins at the lower end of the spectrum with acute language and social impairment, up to the slightly improved functioning Autism and finally less impairment in Asperger's Syndrome. Autism is a

neurodevelopment disorder with early childhood onset (APA, 2000; Moldin & Rubenstein, 2006; Wing, 1993). Specific symptoms of autistic disorder, as outlined in the DSM-IV-TR, are (a) delayed and disordered language development, (b) impaired social interaction, (c) repetitive and/or stereotyped behavior, and (d) often islands of remarkable knowledge sets despite other cognitive impairment (APA, 2000). Children diagnosed with Autism may also exhibit aberrant or aggressive behaviors, such as screaming, hitting, biting, and repeatedly lining up objects (Sigafos, 2000; Murphy et al., 2005).

Individuals diagnosed with ASD present with social impairment that ranges from mild to more profound impairment. It must not be assumed that this impairment means that a desire for social contact is lacking. Many individuals with High-functioning Autism and Asperger's Syndrome have communicated their desire to make friends and their frustration with their lack of ability to do so (Church, Alisanski, & Amanullah, 2000; Myles & Simpson, 2002). The Autism spectrum involves a "triad of impairment" (APA, 2000; Wing et al., 2011). This triad includes difficulty with (a) social interactions, (b) social communication impairment and (c) restricted areas of interest or excessive and repetitive behaviors. Individuals with ASD exhibit impairment in social interactions throughout the entire course of their life (Beadle-Brown, Murphy, & Wing, 2006; Stone, Baron-Cohen, & Knight, 1998). Interactions with others are further complicated not only by unusual verbal skills but also by their inability to interpret and appropriately respond to nonverbal communication (APA, 2000). Individuals with autism may understand concrete concepts and simple directions but will struggle when expected to comprehend

the nuances of language that are utilized to convey irony, humor, or poetry (APA, 2000; Bigham, 2008).

Autistic individuals tend to possess restricted interests and/or repetitive proprioceptive behaviors. I have witnessed restricted interests that include an almost obsessional focus on trains, numbers, fabric texture, items of clothing and sport related statistics. Repetitive behaviors can include rocking, sideways eye gaze, hand flapping and a variety of self-injurious behaviors, particularly when the individual is experiencing frustration. Individuals diagnosed with low functioning ASD explain that a great deal of frustration is felt when interacting with the “normie” or “neurotypical” (normal) population. Many individuals maintain a strict routine and will exhibit serious distress or violent behavior if the routine is altered (APA, 2000). Individuals with ASD have reported that hypersensitivity to auditory and or visual stimulation can excite them resulting in repetitive self-stimulatory behaviors or overwhelm them to the point of self-abusive behavior.

### **Autism Versus Asperger’s Syndrome**

An individual with Autism could be completely non-verbal or echolalic, whereas an individual diagnosed with Asperger’s disorder will present with relatively normal language, only notable for abnormal prosody or volume (APA, 2000; Freeman, Cronin, & Candela, 2002; Meyer & Minshew, 2002).

**Behavioral profile.** Distinctions between Autism and Asperger’s Disorder can be controversial, as some believe that they are spectrum indicators of one diagnostic impairment whereas others believe that they are separate diagnosis. Currently the two diagnoses can be distinguished using language development as a marker. Individuals with

an ASD who do not present with marked early language delay or mental retardation would be diagnosed with Asperger's disorder, also referred to as Asperger's syndrome (Church et al., 2000; Myles & Simpson, 2002). Language impairment in Asperger's syndrome tends to be pedantic or monotonic speech. These individuals have difficulty understanding and responding to non-verbal social communication. The repetitive behaviors individuals with Asperger's Syndrome are expressed as circumscribed interest on a particular topic (Attwood, 2007; Meyer & Minshew, 2002; Myles & Simpson, 2002; Prior, 2003). They become intensely absorbed in their own circumscribed topics of interest and social interactions tend to be one-sided as if they are lecturing as opposed to having a shared conversation. These difficulties cause severe impairment in securing friendships.

Although one may engage in an intellectual conversation with an individual diagnosed with Asperger's disorder on their particular area of interest, the aforementioned symptoms are evident when the individual is inflexible to new topics of conversation and does not respond to nonverbal cues such as a person exhaling in annoyance or even walking away from the conversation (Church et al., 2000; APA, 2000; Bauminger, 2002; Griswold, Barnhill, Myles, Hagiwara, & Simpson, 2002; Myles & Simpson, 2002). The individual with Asperger's disorder will continue talking or they may even follow the person as they exit to another room, speaking to their back as they leave. The individual may desire to relate with others but will be unable to initiate an interaction or maintain the relationship in a socially appropriate manner (Church et al., 2000; Frith, 2004; Rinehart, Bradshaw, Brereton, & Tonge, 2002). Ill-coordinated

movements can cause difficulty in making friends when they stand out as awkward in gym class making them susceptible to bullying.

**Cognitive function and neurology of Autism spectrum disorders.** There is growing empirical support for genetic contributions in deciphering the etiology of the ASDs. McKelvey, Lambert, Mottron, and Shevell (1995) observed abnormal right hemisphere function in three individuals with Asperger's syndrome. Through the use of computed tomography scanning, magnetic resonance imaging (MRI), and single photon emission computed tomography scanning, an enlargement of the right lateral ventricle could be observed. Cerebellar abnormalities and right hemispheric atrophy resulting from the enlargement of the ventricle were noted in all three participants.

Using quantitative magnetic resonance imaging (MRI), McAlonan et al. (2002) compared the neuroanatomy of 21 adults with Asperger's syndrome to 24 healthy control subjects. The investigators found age-related differences in the volume of cerebral hemispheres and caudate nuclei. They found that individuals with Asperger's syndrome had less grey matter in fronto-striatal and cerebellar regions than healthy control participants.

In a longitudinal study, Hazlett et al. (2005) analyzed the MRIs of the gray and white matter brain volumes and head circumferences of children diagnosed with Autism. For the MRI comparison, Hazlett et al. (2005) compared 51 ASD children with a control group of 25 age-matched peers between 18 to 35 months of age. The control group was modified to consist of 11 children with a developmental disability and 14 typically developing children. The ASD children were found to present with enlarged total brain volume, total cerebral cortical volume, total gray matter, and total white matter volume

when compared to the control group. The researchers found that children diagnosed as having an ASD presented with significant enlargement in cerebral cortical volumes and significantly larger head circumference by age two years. No differences between hemisphere sizes or cerebellar volumes were found. To measure head circumference, Hazlett et al. (2005) retrospectively reviewed and compared medical records of 113 children diagnosed as having Autism from birth to age four with 189 typically developing children. There was no significant difference in head circumference at birth between the two groups; however, growth curves were found to begin to diverge at about 12 months of age, at which point children with ASD continued on an increased growth rate greater than that of their typically developing peers. Body mass index (BMI) was calculated to determine if the increase was due to a general increase in body size for the ASD participants; however, no difference in BMI was found.

More creative attempts to determine the neuroanatomical factors that could contribute to the development and expression of ASDs have focused on deficits specific to the disorder. Individuals diagnosed with an ASD are found to have difficulty on mentalizing tasks in which they are expected to understand the mental states of others (Hamilton, Brindley, & Frith, 2009; White, Hill, Happé, & Frith 2009). This deficit is referred to as the Theory of mind theory of ASD. One's ability to respond to others appropriately given an understanding that the individual can have a variety of mental states which differ from one's own (White et al., 2009). To make inferences about how others may feel or think at any given time is necessary when engaging in complex social interactions.

Stone et al. (1998) delineated the theory of mind ability to include several distinct stages that could be measured using social reasoning tests that increase in difficulty. They found that individuals with bilateral orbito-frontal lesions presented with the same difficulties as individuals diagnosed with Asperger's disorder. These individuals were able to successfully navigate first- and second-order theory of mind tasks; however, they experienced difficulty with detecting a faux pas task. Faux pas task errors were not due to a problem with understanding the mental states of the characters in the story presented or due to cognitive limitations in Asperger's disorder or orbito-frontal cortex injured patients. Errors involved problems connecting theory of mind inferences with an understanding of emotion. This possibility was cited as being related to the amygdala and orbito-frontal cortex's involvement in understanding the significance of the actions of others and interpreting the importance of another person's intention. The researchers also posited that this performance was consistent with the behavioral difficulties present in the participants' everyday functioning. Just as noted for Asperger's disorder, individuals with orbito-frontal cortex damage "frequently say inappropriate things and inappropriately analyze social situations" (Stone et al., 1998, p. 648).

Another approach to understanding the abnormal neurological mechanism involved in theory of mind ability is referred to as mentalization. During mentalization activities, 10 adults with autism and Asperger's syndrome presented with neural functioning that was quite different from average functioning age matched controls (Castelli, Frith, Happé, & Frith, 2002). Individuals with Autism and Asperger's syndrome showed less neuronal activation in the mentalizing network. Neural activation was observed to occur in the medial prefrontal cortex, superior temporal sulcus at the

temporal-parietal junction, and temporal poles in the control group. The investigators suggested that the difficulty in mentalizing is a bottleneck in the interaction between different perceptual processes for individuals with Autism.

In an attempt to assess the functional integrity of the neuroanatomy of individuals with Asperger's syndrome, Suzuki, Critchley, Rowe, Howlin, and Murphy (2003) measured the odor detection threshold and odor identification of 12 adult males with a mean age of 33 years. Results indicated that individuals with Asperger's syndrome were significantly impaired in olfactory identification as compared to age matched control subjects.

Some investigators theorized that autism is best conceptualized as what is often referred to as an "extreme male brain." This extreme male brain theory (EMB) was supported by the findings that individuals with autism were found to possess heavier brains and a larger amygdala. These are all characteristics typical of the male brain, which weighs more and has a larger amygdala than the female brain (Harden, Minshew, Mallikarjunn, & Keshavan, 2001; Hazlett et al., 2005). Support for this hypothesis include characteristics observed in the ASD population such as: higher prevalence of ASD in men versus women, heavier brain in neurotypical males, slower social development in neurotypical males and the ratio in finger length of the second to the fourth digit (2D:4D ratio) is lower in men than women and even lower in individuals diagnosed with an ASD (Knickmeyer & Baron-Cohen, 2006). Auyeung et al. (2009) measured fetal testosterone levels that were taken at routine prenatal amniocentesis. The researchers found that both male and female infants who were prenatally exposed to



higher levels of fetal testosterone were rated as presenting with more sexually differentiated play behavior.

**Prevalence.** Prior to the year 2000, epidemiological studies stated prevalence rates as two to five cases of autistic disorder for every 10,000 individuals (APA, 2000). In 2011, the prevalence of autistic disorder was reported to have increased from two to 20 cases per 10,000 people (APA, 2000; Croen, Grether, Hoogstrate, & Selvin, 2002). From 1995 to 2007, the number of children diagnosed with an ASD that received services from the California Department of Developmental Services increased from 0.6 to 4.1 in 1,000 (Schechter & Grether, 2008). The increase in prevalence has been hypothesized to be a result of a combination of factors including the broadening of the Diagnostic and Statistical Manual of Mental Disorders-IV-Text Revision (APA, 2000), increased public awareness, and increased usage in cable television, allergen discussions, and food additives concerns. Empirical research on the increase in prevalence has indicated that an improvement in mental health and medical practitioners' ability to diagnose autism, increased public awareness, changes in diagnostic criteria, and the added incentive of obtaining reimbursement for related therapies have all contributed to the increase in diagnosis (Croen et al., 2002; Waterhouse, 2008).

However it is important to note that review of data collection methods by Taylor (2006), calls the increase in prevalence into question stating that the increase may be due to increased professional and public knowledge of the disorder. Coe et al. (2008), found that an increase prevalence reported in a school in Canada was due to a number of children who had changed their diagnostic classification to an ASD.

**Treatment.** As of yet, there are no empirically supported curative treatments for symptoms associated with the ASDs. Many treatments have been developed based on anecdotal evidence; however, with the exception of one approach, scientific evidence for treatment efficacy continues to be lacking. Kabot, Masi, and Segal (2003) refers to these unsupported treatments as the “cure of the month” phenomenon. Excitement over new “cures” quickly spreads throughout the community of caregivers due to information being easily accessible on the Internet. In addition, Kabot et al., (2003) noted that the Internet is serving as a direct referral source for programs, therapies, and products for parents of children with ASDs. They stated that parents must use the utmost caution when navigating through this information as much of it has not been held up to the professionally-based peer review process required of empirical evidence. Because of the accessibility of misleading information, it is up to the mental health professionals to equip parents with the skills needed to navigate and assess treatments that are safe for their children.

There are a multitude of treatment approaches available for the treatment of symptoms associated with autism, including vitamin therapy, elimination diets, facilitative communication, and speech therapy; however, there is currently no known scientifically supported cure for autistic disorders, symptoms are lifelong (APA, 2000). The treatment most cited in the literature as showing empirical evidence for improving behavioral and cognitive symptoms associated with ASD is intensive adaptive behavioral analysis (ABA), also referred to as applied behavioral analysis or discrete trial training (Huber & Zivalich, 2004; Lovaas, 1987). In an ABA program, children are taught a variety of skills via discrete operant training. General academic, social and daily living

skills are taught using a systematic process utilizing external positive reinforcement to increase desirable behavior in a one-on-one environment. Once individuals can successfully perform a desired task independently, the skill is generalized in the natural environment. The overriding philosophy of this treatment approach is to create a situation where an individual can succeed in achieving a skill through error free trials.

Encouragement is offered through external reinforcement since internal reinforcement may not be intrinsically motivating (Huber & Zivalich, 2004). The experience of success is increased by breaking a more difficult task into smaller, easier to accomplish parts.

Punishment is not used. Through the careful and consistent use of ABA programs specifically designed for an individual with symptoms associated with autism, individuals can be capable of achieving cognitive restructuring that will enable them to behave with increased developmentally appropriate social interest (Huber & Zivalich, 2004).

### **Applied Behavioral Analysis**

Although there is no clearly documented cure for autism, research suggests that the problematic symptoms associated with ASD can be managed effectively using comprehensive behavioral and educational approaches (Kabot et al., 2003; Wing, 1997). Wing (1997) asserted that the most effective way to help children with an ASD is through structured education that is designed to maximize their abilities while minimizing their behavioral disturbances. Furthermore, it is important to provide parents with sufficient information and guidance to facilitate an organized, predictable environment at home for the child. When an individual with ASD is no longer school age, individuals who are not able to live independently require ongoing accommodation, occupation, and leisure activities tailored to their special needs (Wing, 1997).

Lovaas (1987) was the first to develop systematic and comprehensive behavioral intervention programs for children with autism. The basic tenet of behavioral analytic intervention is to deconstruct and organize the behavioral symptoms of autism into specifically defined skill domains. Thus, the goal with ABA is to reduce the maladaptive behavioral excesses while increasing the social and communicative deficits. More specifically, the treatment protocol established by Lovaas (1987) in the Young Autism Project (YAP) relied on discrete trial discrimination. Receptive skills beginning with compliance, for example simple commands such as “sit down,” “look at me,” and “put here” are practiced with a behavioral tutor throughout all of the child’s waking hours. Aggressive and self-stimulatory behaviors were extinguished by: ignoring the behavior, punishing the behavior using a “time out,” or redirect the child to engage in alternative behaviors associated with a differential reinforcement.

The landmark study by Lovaas (1987) reported the significant effect of this behavior modification treatment for two groups of young children with autism. The 19 children in the experimental group began treatment at an average age of 34.6 months ( $M = 2.88$  years). Treatment was considered to be intensive and consisted of 40 hours/week of discrete trial on a 1:1 basis for two or more years. Children in the first control group began treatment at an average age of 40.9 months ( $M = 3.41$  years) and received 10 hours/week of the same type of 1:1 discrete trial for two or more years. At follow-up, children in both groups were between six and seven years of age. The children in the second control group did not receive any treatment from the YAP but were receiving unspecified treatment elsewhere.

Two outcome measures were used at follow-up to determine the efficacy of the behavioral intervention: Intelligence Quotient (IQ) and educational placement (EDP). The IQ was assessed using the WISC-R with at least seven different measures of cognitive functioning or development at intake including the following: WISC-R, Stanford-Binet, Peabody Picture Vocabulary Test (PPVT), Wechsler Pre-School Scale, Bayley Scales of Infant Development, Cattell Infant Intelligence Scale, and Leiter International Performance Scale. The EDP was measured by a nominally scaled rating system comprised of the three following factors: IQ score, class placement, and promotion/retention. Specifically, a child received a score of three if he or she obtained an IQ score in the normal range, completed first grade in a regular classroom, and was advanced to second grade. Additionally, a score of two was assigned to a child who was placed in a smaller classroom such as a resource room. A score of one was assigned to a child who was placed in a classroom for students with autism and/or mental retardation and received an IQ score in the range of severe mental retardation.

Lovaas (1987) reported that almost one-half, 47%, of the participants in the experimental group “recovered” from their childhood autism at follow-up based on having IQ scores in the normal range ( $M = 107$ , Range = 94–120) and successfully completed the first grade in an regular, non-special education classroom. Furthermore, almost 90% of all of the children in the experimental group showed substantial improvements in intellectual functioning, that is, a gain of an average of 30 IQ points, and were placed in less restrictive educational placements such as language aphasia classes, in comparison to both control groups. No children in Control 1 “recovered,” while only one child in Control 2 “recovered” spontaneously.

McEachin, Smith, and Lovaas (1993) conducted a long-term follow-up study and collected additional information from other measures such as the VABS and personality inventory for children from parents of all three groups initially studied by Lovaas (1987). The children in the experimental group were assessed between the ages of nine and 19 ( $M = 13$  years), while the children in the first control group were studied between six and 14 years of age ( $M = 10$  years). The children from the second control group in which there was no behavioral treatment administered were not available for the follow-up study. The children in the experimental group maintained IQ gains ( $M = 84.5$ ) at a mean age of 13 in comparison to the mean IQ of 54.9 for the children in the first control group. Nine of the children with the most successful outcome from the experimental group had a mean IQ of 111. Their parent-reported adaptive behavior scores in communication, socialization, and daily living skills in the average range, and absence of psychopathology based on parent report. McEachin et al. also further discussed the development and main results of Lovaas and reiterated how effective treatment for autism and other severe behavioral disorders required intervention that was delivered early and on an intensive basis by all significant individuals, for example, teachers, therapists, and parents, for many years.

Despite promising results from Lovaas (1987) and McEachin et al. (1993), a number of methodological concerns have been identified for both internal and external validity. This compromises the interpretation of results and claims made for both the efficacy and effectiveness of this treatment. Specifically, it was identified that instrumentation, statistical regression, and selection biases were noted to be three fundamental threats to internal validity (Gresham, Beebe-Frankenberger, & MacMillan, 1999). The study by Lovaas did not use a true experimental design. Rather, it was

comprised of a quasi-experimental matched pairs design in which participants were matched rather than randomly assigned to groups. In addition to the lack of random assignment to groups, participants were not randomly sampled from the population of children with autism. Furthermore, Lovaas initially used only two outcome measures to index the efficacy of treatment: IQ and EDP. Additionally, no independent researchers have replicated the study by Lovaas using the same treatment intensity, that is, 40 or more hours/week of 1:1 discrete trial for two or more years, thereby creating a further void in external validity of his intervention. Legal and ethical hazards were also present in the treatment protocol of Lovaas. In severe displays of inappropriate behaviors, physical and verbal punishments delivered to the children were in the forms of a slap on the thigh and reprimands such as a very loud “No!”

### **Empirical Support for Applied Behavioral Analysis**

Although muddled with methodological and design flaws, numerous researchers have demonstrated the effectiveness of behavioral treatment on autism, especially when making comparisons to other approaches which do not that have the same degree of empirical support (Shriver, Allen, & Mathews, 1999). Additionally, there is agreement on certain factors related to behavioral and educational interventions on the following criteria: (a) intervention should be provided at the earliest age possible; (b) intervention must be intensive; (c) parent training and support should be a component of the program; (d) the curriculum should focus on social and communicative domains; (e) instruction should be systematic with individualized goals and objectives; and (f) particular emphasis should be put on generalization of new skills (Kabot et al., 2003).

Strain and Schwartz (2001) reviewed a number of instructional strategies derived from ABA and paid particular attention to the social validity and sustainability of behavior change. The authors asserted that meaningful social relations should be the primary outcome goal of educational programs for young children with autism. Furthermore, interventions should be more intensive, comprehensive, and ecologically valid to produce the level of behavior change demanded by the social world.

Bauminger (2002) studied the effectiveness of a seven-month cognitive behavioral intervention program. The intervention focused on the facilitation of social-emotional understanding and social interaction in 15 high-functioning children with autism ranging in age from eight to 17. This specific type of intervention focused on teaching interpersonal problem solving, affective knowledge, and social interaction. Results demonstrated progress in the following three areas targeted by the intervention: (a) greater likelihood of initiation of positive social interactions with peers, as exemplified by improved eye contact, sharing of experiences, and more interest in peers; (b) more relevant solutions and fewer nonsocial solutions to different social situations; and (c) increased identification of complex emotions, which were supplied by more specific rather than general examples and included an audience more often in the different emotions. Teachers also rated higher social skills scores in assertion and cooperation after treatment in the children with autism.

Gresham et al. (1999) conducted a comprehensive review of empirically supported treatment programs for children with autism. The empirical evidence on the treatment efficacy and effectiveness of the University of California Los Angeles (UCLA) Young Autism Program, Project Treatment and Education of Autistic and Related



Communication Handicapped Children (Project TEACCH), Learning Experiences and Alternative Programs for Preschoolers and their Parents (LEAP), applied behavior analysis (ABA) programs, and the Denver Health Science were assessed using the conventional standards of research design and methodology of the Division 12 Task Force on Empirically Supported Treatments for Childhood Disorders of the American Psychological Association. Based on these task force criteria, there are no well-established treatments for autism; however, virtually all of the aforementioned behavioral programs produced substantial developmental gains, particularly in IQ.

### **Raising a Child With an Autism Spectrum Disorder**

The task of parenting a typically developing child can certainly be a stressful task; however parenting a child with an ASD can exponentially increase one's stress load. In Poland, Dabrowska and Pisula (2010) investigated parents raising a child diagnosed with a developmental disability: ASD versus Down's Syndrome. They found that parenting a child with Autism was rated as more stressful than raising a child with Down's syndrome. As a result of the increased stress, parent support is encouraged as an important element of the treatment program (Osborne & Reed, 2010).

In addition to the burden of having a child who is more difficult to raise, another stress for parents of an individual diagnosed with autism is that, because it is a pervasive disorder, caregivers must navigate a lifetime of therapies and or assistive living for the entire course of the individual's life. These therapies can include a multitude of professionals, advocates, lawyers, visiting one's home, frequent interaction with medical and mental health professionals and the bi-annual individualized educational program meetings (IEP's) associated with their school district. Moldin and Rubenstein (2006)

estimated that such therapies can cost up to \$3.2 million per person diagnosed with autism over the individual's lifetime.

Many parents report that they must work through a mourning period following their child's diagnosis prior to achieving a state of acceptance of their child's limitations. At that point, caregivers can finally develop realistic expectations for their own and their child's future (Bilgin & Kucuk, 2010). To make matters worse, some families have been to several mental health professionals and received a variety of diagnosis that focus on specific elements of the child's disability before they are given the ASD diagnosis (Wilder, Dyches, Obiakor, & Algozzine, 2004). Paraprofessionals need preparation for the types of stress that these families have experienced prior to entering their home as a behavioral tutor.

### **Cultural Issues in the Treatment of Autism Spectrum Disorders**

Although current research on multicultural issues in ASD is limited, investigators across the world are beginning to question whether current treatment approaches are serving diverse populations effectively (Bernier, Mao, & Yen, 2010; Kapp, 2011). Language barriers and communication style when obtaining a diagnosis, advocating for their child, and for engaging in parent training, are cited as posing the greatest difficulty for minority families. Interpretation of behaviors associated with ASD can be affected by the individual's cultural lens. For example, Navajo caregivers did not report self-stimulatory behaviors as being an area of concern whereas more westernized families may indicate it as a major issue to address (Connors & Donnellan, 1998).

When diagnosing a mental health problem, professionals must determine whether the presenting symptoms and behaviors are within mainstream, culturally acceptable

norms, and whether it causes distress and disability to the individual (Levin & Schlozman, 2006). In the Netherlands, Begeer, El Bouk, Boussaid, Terwogt, & Koot, (2009) presented 82 pediatricians with six vignettes that differed in ethnic background and every two included one to three autism related features. A bias in spontaneous clinical judgment was found resulting in an under diagnosis for ethnic minorities. This under diagnosis was eliminated when explicit instructions to rate the likelihood that the diagnosis was associated with an ASD was given. Investigators also found that ASD children from ethnic minorities were underrepresented in the populations of their three major mental health institutions specializing in the treatment of Autism Spectrum Disorders.

Due to culture bound child rearing practices, caregivers may not feel comfortable incorporating the recommendations of a mental health specialist (Trembath, Balandin, & Rossi, 2005). In the Midwestern United States, Jegatheesan, Fowler, and Miller (2010) interviewed six biological parents, from three families of South Asian decent, living with a young ASD child. Interviews were conducted in the caregivers' native tongue (Hindi, Urdu and Arabic) focusing on their reactions to the diagnosis, understanding of etiology, treatment, process of obtaining services and experiences with professionals. The interviews revealed cultural reasons for a delay in diagnosis. When caregivers raised concern about their child's loss of language, family and community members explained that "boys speak later than girls" (Jegatheesan et al., 2010, p. 803) so that there was no reason to worry. Post diagnosis, members of the family and community sought to understand how the mother had "damaged the child's brain" (Jegatheesan et al., 2010, p.804) prenatally, pointing to superstitious beliefs about improper diet and evil omens.

Parents cited their frustration with mental health professionals' use of jargon and their perception that the professional did not involve elders living in the home as collaborators in establishing treatment goals for the child.

In general, expectations of caregivers can vary greatly. It can range from expecting their child to be cured of all associated ASD symptoms and others for their child to require lifelong assistance and to live in a residential mental health facility. Culturally based interpretations of how one is expected to contribute to the greater society can also affect caregiver expectation (Wilder et al., 2004). For example, some families may believe that the individual with ASD will spend the entirety of their life in the family home versus holding a job in the community. To complicate matters of caregiver expectations, there is a phenomenon referred to as the "cure of the month." These cures are new and not yet validated treatments that frequently promise to eradicate symptoms associated with Autism (Offitt, 2008). These treatments can be costly and sometimes dangerous but tend to appear more appealing than daily behavioral tutoring, which sometimes produces slower or less dramatic progress. This can overwhelm and frustrate caregivers who do not want to feel as though they have given up hope for their child's outcome.

There also exists a group of individuals who proudly identify themselves as being Autistic or being "Aspie," diagnosed with Asperger's Disorder. There is a culture of disability in which some people identify strongly with their diagnostic label. They are proud to be identified as being "Aspie" and refer to other non-ASD people as "neurotypicals. It is important for paraprofessionals to understand that people who are proud of their identity as it relates to these diagnosis, can sometimes feel insulted when

presented with advocacy efforts focused on curing their Autism as if were an ailment. These groups have also voiced their frustration over the proposed DSM diagnostic change in which Asperger's Disorder will be subsumed into the Autism spectrum as opposed to being a separate diagnosis.

Empirically supported treatment of ASD symptoms involves early intervention, which can begin when a child is as young as 2 years of age. The home-based ABA program involves paraprofessional behavioral tutors spending sometimes 30-40 hours in the client's home engaged in intense behavioral tutoring. Grindle, Kovshoff, Hastings, and Remington (2009) interviewed 53 parents whose Autistic children had received at least 2 years of ABA tutoring for up to 40 hours per week. They found that although parents supported ABA as being helpful for their child and family, that this home-based treatment presented several challenges. Families cited their struggle to fund the program whether it consisted of acquiring funding through their local educational system, regional center or by funding it themselves (using the child's college savings, their own savings, mortgaging their home) as being of concern. Caregivers also cited a variety of difficulties with working with the behavioral tutors whom conducted tutoring within their home. Some of the problems stemmed from a lack of professionalism (last minute cancellations, frequent tardiness, poor interpersonal boundaries), high turnover of tutors, as well as the discomfort of having numerous people in one's home on a regular basis.

### **Native American History**

**The historical relationship between public services and Native American people.** To understand the current state of the relationship between government services and the Native American people, it is important to refer to the tragic history with the

services established by the early colonizers. As a result of broken treaties and treatment which was intended to strip the Native Americans of every aspect of their culture, many Native Americans continue to harbor a great deal of distrust for the laws and governmental boundaries enforced by the early colonizers (Bee & Gingerich, 1977). This very same distrust has been transferred over to other institutions including those that provide mental health treatment. Mental health services tend to be underutilized by the Native American population despite the fact that according to the *Diagnostic and Statistical Manual*, the rates of the occurrence of mental health illness within the Native American population is comparable to the general American population (Bichsel & Mallinckrodt, 2001).

**Providing mental health services to Native American families.** Mental health services for the Native American population have been included within general health services since their inception in 1803. In order to limit the utilization of traditional healing approaches, the War Department created a smallpox prevention program. Medical services were passed from military to civilian management in 1894 to the Bureau of Indian Affairs (BIA), whose leaders attempted to establish more expansive health care and education for Native Americans. In the 1930s, care continued to address physical ailments although sanitariums were available. Finally, in 1975, the ‘self-determination act’ was passed to move these responsibilities from the BIA to a division of the Department of Health and Human Services referred to as the Indian Health Service (IHS).

#### **Legal History: Timeline of U.S. government involvement with Native Americans**

1785 Hopewell Treaty—The Hopewell Treaty required that Cherokee, Chickasaw, and Choctaw tribes allot land for white settlement.

1819 Civilization Fund Act—The Civilization Fund Act provided grants to private agencies (usually religiously affiliated) to establish programs to “civilize” or assimilate the American Indians.

1830 Indian Removal Act—The Indian Removal Act authorized the American president to conduct treaties to exchange American Indian land east of the Mississippi River for land west of the river. Relocation to reservations was supposed to be voluntary. Many died, wiped out by diseases such as smallpox and measles introduced by colonizers.

1832 Indian Vaccination Act—The Indian Vaccination Act was the first program created to address American Indian health problems.

1857—Native Americans were “free and independent people” who could become U.S. citizens.

1884 “Placing out” system—The “placing out” system placed American Indian children on farms away from their families and tribe in the east and Midwest so they could learn the “values of work and the benefits of civilization.”

1924 Indian Citizenship Act—The Indian Citizenship Act granted U.S. citizenship to all Native Americans. Many had already become citizens through treaty provision, registration, and land allotment under the Dawes Act of February 8, 1887, or by enrolling in the armed forces.

1953 Public Law 280—The 1953 Public Law 280 passed civil and criminal jurisdiction from the federal government and local tribes to the state in which the reservation was located. Part of the motivation for this law was to make American

Indians eligible for state-administered services such as public assistance and child welfare services.

1959 Indian Adoption Project—The Child Welfare League of America, in cooperation with the Bureau of Indian Affairs, initiated the Indian Adoption Project. In the first year of this project, 395 American Indian children were placed for adoption with non-American Indian families in eastern metropolitan areas. With no attention to preserving the Indian family, it was yet another “ultimate indignity to endure.”

1975 Indian Self-Determination and Education Assistance Act—The Indian Self-Determination and Education Assistance Act encouraged self-government among Native Americans. Five hundred sixty-two federally recognized tribal governments in the United States could create their own government, enforce civil and criminal laws, tax, and devise requirements for membership. “It enabled the tribes to provide their own police protection” (Clark, 2005, p. 23). Currently there are four possible types of police agencies found on a reservation: the Bureau of Indian Affairs, tribal police, federal law enforcement, and state and local area law enforcement.

1976—A study conducted by the Association on American Indian Affairs found 25-35% of all American Indian children were placed in out-of-home care and 85% of those were placed in non-American Indian homes or institutions. Loss of their children was contributing to the loss of American Indian culture.

1978 Indian Child Welfare Act (ICWA)—The ICWA has two provisions designed to protect American Indian families and culture. First, the ICWA sets up requirements and standards for child placing agencies to follow in the placement of American Indian children. The provision of remedial, culturally appropriate services for



American Indian families before a placement occurs were mandated, notifying tribes regarding the placement of American Indian children, and when placement must occur. The act also requires that children be placed in American Indian homes. Second, the act provides for American Indian tribes to reassume jurisdiction over child welfare matters including developing and implementing juvenile codes, juvenile courts, tribal standards, and child welfare services.

### **Factors Related to Underutilization and Access to Health Services**

Access to mental health services for Native Americans have improved with the organization of Indian Health Services along with the organization and recruitment of Native American mental health providers; however, these services continue to be underutilized. Determining which healthcare system is used is sometimes dependent on whether a family lives closer to and has access to Indian Health Services or mainstream health care centers. A family living on more rural tribal land may have to travel great distances at great expense to obtain mental health services. Another complication is that the federal government does not recognize all tribes as sovereign nations. This means that unrecognized tribes are not considered independent from the U.S. government therefore, they are not permitted to govern themselves out of the jurisdiction of U.S. law and are ineligible for aid through Indian Health Services as well as U.S. social services.

**Historical trauma.** As one explores the historical context that shapes the current Native American collective experience, one cannot deny the impact of historical trauma. Contemporary Native Americans are survivors of genocide and intergenerational trauma. It cannot be denied that there exists a tragic lineage of damaging emotional and mental experiences that have been passed down through each generation, either directly resulting

from the genocide experience or as the result of being raised by caregivers who are struggling themselves to recover from their own trauma experiences, such as domestic abuse, substance abuse, lack of resources, money, food, and/or education. As a culture, Native Americans possess many adaptive coping practices and ceremonies utilized to deal with traumatic experiences; however, many of these practices were outlawed during the mainstream culture's attempt to "civilize" them, at a time when they needed it the most. Native Americans were not allowed the time to heal before incurring further trauma.

**Boarding schools.** After the American Civil War (1861-1865) and Indian wars (1811-1890), one of the federal programs, designed to "civilize the Indian," implemented the use of American Indian boarding schools. In 1819 the U.S. government created the Civilization Fund Boarding Schools, which were large militaristic or mission schools for American Indian children 3 to 13 years old. These schools were sometimes referred to as the "Indian School Experiment." Many of the schools were gravely overcrowded; some were reported to house more than 1,000 students. The federal education system was given the responsibility of taking on what was commonly referred to by early colonizers as the "Indian problem," a term meant to refer to the process of assimilating the indigenous people to the more Eurocentric way of life followed by the early colonizers. The belief was that this education would require the removal of Native American children from their families and communities so that they could be prepared for "citizenship and all the rights and responsibilities appurtenant to it" (Dejong, 2007, p.257).

The use of boarding schools enabled colonizers to assimilate the Native American children into their own mainstream society. In an attempt to extricate their "savage" way

of life Native American children were required to wear European style clothing, speak only English, and receive European style haircuts in order to receive food and housing (Dejong, 2007). Use of their indigenous language was grounds for sometimes severe punishment. Many of the schools belonged to religious organizations that also required the children to conform to their religious practices while using punishment or restriction from resources or other freedoms if the children were caught performing Native American ceremonies. Unfortunately, for the Native American children and their families, these schools became increasingly oppressive, even making it illegal for Native Americans to use their native language in a federal school. Several hours a day children were required to perform manual labor in dangerous and unhealthy conditions under the conviction that this would prepare them for the kinds of jobs they were capable of performing as adults.

During the boarding schools' inception, Native American caregivers were reluctant to send their children to Indian boarding schools as they were known for having a high rate of mortality. According to Dejong (2007), students attending Indian boarding schools experienced double or triple the national rates for contracting smallpox, measles, trachoma, chicken pox, tuberculosis, and the mumps. At the Fort Apache Indian School dormitory, in order to prevent students from escaping the school, the windows were nailed shut, preventing ventilation in the dormitory where students slept three to a single bed. This environment mixed healthy with infected children increasing the spread of infection. One example cited that 11 out of 15 Shoshone boys died after they were sent to the Carlisle Indian School, located on a deserted military base in Pennsylvania. It was not uncommon for infected children to be sent home before they passed away, thereby

increasing the likelihood of infecting the rest of their families and community of origin (Dejong, 2007).

In 1910, boarding school workers were granted bonuses for taking a leave of absence with the sole purpose of forcibly collecting as many Native American children as possible from the surrounding reservations by whatever means necessary. The Virginia Company authorized and offered cash rewards for the kidnapping of Native American children with the goal of “civilizing” Native American populations through Christianity. Even in 2011, many Native American descendants recall being told by their elders to “just run as fast as you can” when an unfamiliar person approaches the reservation for fear that they would be kidnapped and taken to an Indian Boarding School. At Native American mental health trainings it is not uncommon to hear stories about boarding school in which individuals were beaten, humiliated or raped by staff. Following the 100 years of contact that the Native Americans have had with the early European immigrants, the collective experience including large scale massacres, broken treaties and boarding schools, give good reason for suspicion of (both) mainstream Euro-American services, as well as Indian-controlled ones (Guillory & Wolverton, 2008).

The sordid Native American history has contributed to skyrocketing statistics of abuse and mental health issues. Native Americans are overrepresented among the homeless (8%) and among individuals with drug and alcohol problems (as high as 70%) according to the 1999 U.S. Department of Health and Human Services Surgeon General’s Report. Among Native Americans between the ages of 15 to 34, they are 2.2 times more likely to commit suicide than the national average for this age group; suicide is the second leading cause of death for Native Americans. American Indian families are likely

to have been exposed to violence, domestic abuse, suicide, health problems, substance abuse, and the stress of living in two worlds (traditional versus that of the dominant society) in substandard conditions. Their rate of violent victimization reported by the Department of Health is more than two times the national average and a 22% rate of exposure to traumatic events compared to 8% in the general population in the United States. Brave Heart (1998) defined this cycle of historical trauma as, cumulative, collective emotional and psychological wounding. Events such as the past genocidal intent, forced removal of children, abuses sustained in boarding schools, are pervasive and are passed on across generations through continue cycles of violence and depression (Brave Heart, 1998).

A family already burdened with historical as well as current life stress is pushed to the limits when their child is diagnosed with a pervasive developmental disorder such as autism. This diagnosis brings with it the added stress associated with having to work with and navigate through a variety of mental health, medical, educational, and at times, legal agencies, all of which are likely to hail from a different racial and cultural background.

A major barrier to culturally responsive treatment of Native American clients, stems from the fact that most mental health providers possess a more Western/European worldview. There also exists a myopic view of Native American mental health that simply focuses on dysfunction as opposed to the many strengths intrinsic to their culture. The concept of finding balance in one's life through use of the four sacred directions of nature, spirituality, community, and the environment can be used to support and rebuild Native American families in need (Coyhis & Simonelli, 2005; Portman & Garrett, 2006).

Within the Native American community, efforts are being made to strengthen and revitalize the strengths inherent in traditional customs and beliefs.

**Native American communities.** Indian societies have gone through dramatic changes during the past century; yet, there are people in rural areas who can be more rooted in cultural traditions and who hold on to knowledge, attitudes, and beliefs that are quite different from the majority American culture. “While diversity in language, customs, and traditions are typical across tribal societies the essence of traditional life is captured through important markers such as spirituality and relationship patterns among kin,” (Red Horse, 1997, p. 243).

The communities can consist of extended families that resist intrusions, especially by politically organized human services which can be interpreted as being designed to tamper with the sacred ways of traditional Native American life. Extended kin systems are related by blood, marriage, or adoption and are commonly referred to as family. They include vertical and horizontal dimensions. In Sioux tribes, people are talked about using words denoting relationships as opposed to names.

Traditional American Indian communities are known for tolerance of differences. They accept individuals who were on the margin and who in today’s American society would be shunned. Prior to colonization some tribes did not have a word for developmental disabilities. Individual differences are incorporated into traditional societies through a context of spiritual definition. Thus, health characteristics that would be defined as disabilities in the language of America’s human service professions were framed as special strengths in traditional Native American beliefs. It is important to note

that, as with all groups, each Native American individual will vary in their degree of acculturation or socialization into the majority culture.

### **Culturally Responsive Preparation for Professionals Treating Autism Spectrum Disorders**

Although there is a lack of research on multicultural issues in autism, Church et al. (2000), and Wilder et al. (2004) proposed culture specific strategies for meeting the treatment needs of individuals with autism in a culturally responsive manner. They explain that, “If the intention is to prepare professionals to be able to truly serve students with autism, efforts must be made to produce culturally responsive education programs” (Wilder et al., 2004, p. 109). Of paramount importance is having respect for the clients’ with whom they work.

In describing the ideal ABA tutor who works multi-culturally and develops multicultural curricula, investigators suggested that these individuals demonstrate a deep level of understanding and respect of their own cultural heritage and that it is only from this point that they can begin to acquire the knowledge and skills by which to be allowed to work with individuals from cultures different from their own as well as to better serve the mainstream culture. They explain that the characteristics of a culturally sensitive tutor include a curiosity for learning about customs, communication styles, mores and belief systems of different cultural groups. Church et al. (2004) stress that professionals preparing to work with this population must not accept a deficit orientation, but instead they must know how to empower the client and caregivers by way of building upon their strengths. Behavioral tutors must keep in mind that their client and their respective family are resilient, capable and motivated to improve their functioning.

### **Questions Guiding the Study**

The questions guiding the development of this training resource include:

1. What do paraprofessionals need to know, in addition to knowledge contained in the currently available ABA training manuals, to provide culturally relevant treatment to Native American clients within the client's home?
2. What are the essential considerations and skills required to work effectively within Native American homes?
3. Based on the literature available in peer-reviewed journals, what skill sets and treatment approaches have been most effective in working with Native American families? How can this information be synthesized for use in the service delivery of an in-home ABA program treating a child with an autism spectrum diagnosis?
4. How can the aforementioned information be integrated into a paraprofessional training resource to be used by licensed mental health practitioners?

### **Summary and Organization of Remaining Chapters**

**Scope and focus of the study.** Findings from empirical literature will be gathered to present the current understanding of Native American postcolonial history within the parameters of mental health treatments. An overview of culture specific treatment approaches and an overview of the pervasive developmental disorders, which include autism and Asperger's disorder and the accompanying treatment associated with these developmental disorders, will also be presented. This literature will be synthesized into a training resource to train paraprofessional tutors preparing to provide ABA services to



Native American children. The resource will then be reviewed and critiqued by an expert panel of Native American behavioral health specialists.

## **Chapter 2: Method**

### **Objectives of the Scholarship**

The objective of the proposed research was to develop a training resource to be used by mental health practitioners while preparing their teams of paraprofessionals to work as behavioral tutors of Native American children diagnosed with an autism spectrum disorder (ASD). The development of this training resource involved a thorough review of published information from journal articles, research, and existing training manuals. The review included empirically based references to encourage practitioners to responsibly tutor children with ASD and to enable them to navigate the abundance of unsupported treatment approaches targeting this population. The manual included terminology commonly used in the field of Adaptive Behavioral Analysis (ABA) with the goal of being easily used in addition to the basic ABA training. The manual aimed to provide instruction for paraprofessionals to increase their own cultural awareness of their own biases and to serve as an introduction to the positive parenting skills specific to the Native American culture.

This clinical dissertation was intended to contribute to research supporting the more positive or strength based approaches to working with Native American families. The resource manual was intended to be used by trained mental health clinicians in training their teams of paraprofessional behavioral tutors, either individually or in a seminar format. The resource included a general overview of Native American culture and variations within the culture. Exercises at the end of each training module provided a review of the skills presented, as well as an opportunity to analyze one's own cultural beliefs and values. An appendix to the resource manual includes a list of sources that can

be referred to for additional information. Following the formation of the resource manual, a small panel of Native American mental health practitioners were asked to review and provide feedback on the scholarship. Recommendations made by the expert panel are discussed in the results and discussion section of this dissertation.

**Steps for the development of the resource.** Peer reviewed literature currently equips mental health practitioners with a plethora of information on ABA used in the treatment of autism spectrum disorders but very little documentation exists addressing treatment in Native American homes. After carefully reviewing the current academic literature on the subject of culturally appropriate in-home behavioral services for Native American families of autistic children, information was organized and presented in a user-friendly training resource format. It was presented as three training modules to be disseminated over the course of a three-day training. The resource begins with a review of cultural issues related to working within the field of Autism, followed by cultural competency training highlighting one's own cultural beliefs and ending with the last module which focused on the cultural strengths present in Native American families. Training is to be lead by licensed mental health providers in order to prepare paraprofessional ABA tutors. Trainers are expected to have received formal training in cultural competency issues as part of their formal education and licensure. In order to encourage the paraprofessional in training to carefully consider their own cultural beliefs and values, problem solving exercises have been included as well as bulleted take home points which were featured at the end of each chapter.

## **Participants**

A total of three mental health clinicians were recruited to participate in the evaluation of the training resource. This panel of experts was identified through Native American organizations, conferences and networks of the investigator. A potential participant indicated that she did not feel qualified to participate because of her limited experience with Adaptive Behavioral Analysis, however this specialist took it upon herself to share information regarding the project within her own network of mental health professional. Through this contact the author received a third qualified participant as well as the interest of two mental health program coordinators working with the Native American population. One of these coordinators was not able to participate in the resource evaluation due to time constraints but requested that the author utilize her team of mental health specialists for a pilot study of the training following the completion of the project.

Clinical therapists in psychology and other licensed mental health practitioners were asked to review and provide feedback on the usefulness and validity of the resource. All evaluators have at least 3 years of experience working with the juvenile Native American population and with ABA treatment approaches.

## **Procedure**

The licensed mental health professionals whom evaluated this resource were expected to have experience working with the Native American population for a minimum of 3 years. Participation was voluntary, no compensation for involvement was provided. Following the receipt of the completed consent form, the experts were mailed a copy of the manual along with a coded evaluation form (see Appendix E) with an

enclosed self-addressed stamped return envelope. The evaluation form requested a thorough review of the resource followed by Likert ratings pertaining to the applicability and clarity of the training resource, and followed by an open-ended questions pertaining to the strengths and weaknesses of the three training modules. Completion of the five-page evaluation form was expected to take approximately 10-15 minutes to complete.

The collected and reviewed evaluation forms are discussed in detail in Chapter 4. The training resource, including the visual layout of the manual can be found in Appendix F. Recommendations for future revisions of the training resource are included in chapter 4.

### **Summary**

The manual was intended to be utilized by supervising clinicians to function as a training tool, which may be presented in a three-day workshop format. The intended audience was licensed mental health specialists expected to have attained a post-secondary level of education; therefore, a degree of jargon is admitted. A goal is to refrain from repeating the general ABA training that can be obtained from readily available store bought training manuals. This resource focused on the many challenges involved in the application and delivery of ABA services with individuals from Native American homes. To correct for investigator bias, a small group of mental health service providers currently working with the Native American population throughout the United States reviewed the training resource. Their feedback is reported and addressed in the results and discussion chapters.

### **Chapter 3: Training Resource**

#### **ABA in Native American Homes: A Culturally Responsive Training for Paraprofessionals**

**Rationale.** Current ABA training for paraprofessionals to work with children diagnosed with an Autism Spectrum Disorder focuses on behavioral teaching methods. Without knowledge of cultural factors that they will encounter when working in client's home, especially client's of Native American descent, they are likely to experience difficulties that can have deleterious effects on treatment outcome. Mental health specialist responsible for training and for ABA program direction can use this resource to begin a dialogue about cultural competence with their paraprofessionals behavioral tutors. This training resource seeks to elevate the standard of ABA training to include an integral skill set for these paraprofessionals to better serve the Native American population.

#### **Summary and Organization**

**Resource outline.** The training resource was divided into three one-day training modules to be presented over the course of three days.

The resource began with a brief introduction and overview of the Autism Spectrum of disorders. Trainees are asked to discuss how they expected culture to play a part in their work as an ABA tutor, illuminating that the identified child with ASD client is not the only relationship of concern and care, but also all members of the family network. Trainees were presented with the concept of the existence of an Autism culture. Topics such as one's social status, gender and access to resources were discussed.

Module 2 introduced the concept of cultural competence. This module illuminated the importance of the analysis of one's own cultural belief and values. Trainees are expected to consider their own values and beliefs on child rearing, family organization and developmental disabilities.

Module 3 included an overview of the power differential, which exists in the helping professions. A discussion of how the behavioral tutor is perceived by the clients' caregivers and how this role is experienced differently dependent upon the client's identified culture. Western beliefs and assumptions about the behavior of other cultures were discussed. Information on the variation in beliefs and values across Native American tribes was covered. The concept of historical trauma as well as a timeline of the United States involvement with Native American tribes since colonization was presented. The module concludes with the presentation of how using a strength-based approach to cultural competent service delivery versus a deficit-based approach.

A training resource was developed with the objective to provide a culturally responsive ABA training module for paraprofessionals working in Native American homes. The intention is for the training to be delivered to paraprofessional ABA tutors by licensed mental health practitioners acting as ABA program coordinators. Completed Training Resource as it was presented to specialists in the field for review is included in Appendix F.

**Practical contribution of the study.** A training resource preparing behavioral tutors to work with Native American families can improve rapport with the client and their family. Improved rapport can increase program consistency, decrease family stress and improve the client's functioning. From the stand point of an ABA program director,

this additional training can increase professionalism and prevent problematic situation which can arise when paraprofessional mishandle parent concerns. This can increase awareness of cultural issues in general for home-based behavioral tutoring and encourage mental health practitioners to improve the cultural competence training for other minority families with which they treat. Furthermore, should a mental health practitioner be successful in recruiting paraprofessionals from the client's own community, in addition to possessing an increased familiarity with the client's culture, doing so can also create employment opportunities for local Native Americans with high school diplomas or higher (Walkup et al., 2009).



## **Chapter 4: Results**

This chapter provides an overview-summary of the evaluation feedback received from the expert panel.

### **Summary of Review Panel**

Upon consent to participate in the study, participants were asked to review the training resource and to complete a five-page response form. Informed consent and response forms were collected throughout the course of 2 months and were coded in order to ensure confidentiality.

The expert panel, which consisted of three licensed mental health professionals, was recruited to review the training resource and provide feedback on a confidential evaluation form. The professionals were required to be knowledgeable about ABA and autism spectrum disorders and to possess at least 3 years of experience providing behavioral or mental health services to Native American families. Out of four mental health professionals who were contacted, two responded with interest in participating in the review. One participant did not feel qualified to participate because of her limited experience with individuals diagnosed with an Autism Spectrum Disorders (ASD) and took it upon herself to share information regarding the thesis within her network of mental health professionals, producing an additional respondent. Three licensed mental health professionals participated in the review. One of the reviewers identifies as an active tribal members in a registered Native American tribe.

All 3 participants currently provide mental health services with the Native American populations in the regions of Los Angeles, California; Santa Fe and Albuquerque, New Mexico; and Flagstaff, Arizona. Their job titles include: program

owner-coordinator, speech and language pathologist, college professor, behavior specialist, and psychologist. The expert panel presents with an average of 11 years' experience working with the Native American population and an average of 16 years' experience working with individuals diagnosed with Autism Spectrum Disorders (Table 1).

Table 1

*Characteristics of the Expert Panel*

Evaluator	Number of years working with NA	Number of years working with ASD	Licensure-Credentials
1	18	20	Licensed Psychologist, Nationally Certified School Psychologist
2	8	15	Marriage & Family Therapist, Choctaw tribal member, ABA program owner
3	9	15	Certificate of Clinical Competence in Speech & Language Pathology, ABA program owner/coordinator

**Summary of Feedback**

**Evaluator feedback.** Tables 2–15 demonstrate the feedback given by the expert panel.

Feedback was gathered for each training module as well as the overall training resource.

### **Strengths and Weaknesses of Module 1**

Based on a scale from 1 to 5 with 1 signifying “not at all” and 5 “very much so,” all three reviewers indicated that the first module of the training resource provided information that was useful in preparing paraprofessionals to provide home-based treatment to families of a child diagnosed with an Autism Spectrum Disorder ( $M=4.67$ , Table 2). The first module was considered to be somewhat easy to read ( $M=4.33$ , Table 2).

Table 2

#### *Feedback on Training Module 1—Question 1*

Evaluator	Usefulness	Readability
1	5	4
2	5	5
3	4	4

*Note.* 1 = not at all, 2 = not really, 3 = neutral, 4 = somewhat, 5 = very much so.

Evaluator 2 explained that one of the most effective elements of Module 1 is the recognition of the variation in caregiver expectations with regard to treatment and outcome that can vary as a result of one’s cultural identification (Table 3). Evaluator 3 stated that an effective element in Module 1 is the instruction to paraprofessionals that cultural issues are indeed involved in ABA when treating individuals diagnosed with an ASD (Table 3). Evaluator 1 explained that Module 1 presents with a “good introduction” (Table 3) of ABA treatment in the homes of ASD clients.

Table 3

*Feedback on Training Module 1—Question 4*

What aspects of Module 1 were most effective?	
Evaluator	Comments
1	Good introduction
2	Acknowledging that culturally caregiver expectations vary greatly, in regards to both treatment and outcome
3	Cultural issues in treating ASD's

Although Evaluator 1 noted that Module 1 provided very useful information, he or she also indicated that it could be improved with the inclusion of an index (Table 5). This evaluator also indicated that Module 1 could provide a more in-depth explanation on the topic of ABA approaches (Table 4). Evaluator 3 elaborated this suggestion and noted that the module seemed to be lacking a more varied description of ABA. This evaluator went further to recommend that descriptions of similar treatment approaches such as TEACCH and Pivotal Response Training be included within the module (Table 5). Evaluator 1 noted that a more in-depth explanation of ABA would strengthen the training, however developing this section further would unfortunately increase the duration of the training (Table 4). Evaluator 3 noted that he or she would have also liked to have seen information regarding gender differences in caregiver expectations on treatment outcomes among Native American caregivers in Module 1 (Table 4).

Table 4

*Feedback on Training Module 1—Question 3*


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With regard to knowledge and skills needed to work in a culturally responsive manner with the individuals diagnosed with an Autism Spectrum Disorder, what information would you have like to have seen included in Module 1 which may have been lacking?

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Evaluator	Comments
1	More depth on specific ABA approaches – but I realize time and space is limited
2	None
3	It would be important to have gender specific information on any differences in expectations of men vs. women while in Native American homes

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Table 5

*Feedback on Training Module 1—Question 5*


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What suggestions do you have about how to improve the effectiveness of Module 1?

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Evaluator	Comments
1	An index would be helpful
2	None
3	A little more variety on discussion of ABA to include other approaches (i.e. pivotal response teaching, TEACCH)

---

## Strengths and Weaknesses of Module 2

Based on a scale from 1 to 5 with 1 signifying “not at all” and 5 “very much so,” the evaluators felt that Module 2 provided somewhat useful information on the topic area of providing culturally competent home-based ABA treatment ( $M=4.33$ , Table 6). This module was rated as providing a slightly better than average ease of reading ( $M=4.33$ , Table 6).

Table 6

### *Feedback on Training Module 2—Question 1*

Evaluator	Usefulness	Readability
1	4	4
2	5	5
3	4	4

*Note.* 1 = not at all, 2 = not really, 3 = neutral, 4 = somewhat, 5 = very much so.

The cultural guidelines were found to be the most effective instruction of Module 2 according to Evaluator 2 and 3 (Table 7). Evaluator 1 indicated that an effective training element present in Module 2 is the “good explanation of becoming familiar with yourself” prior to working with cultures different from one’s own (Table 7). Evaluator 2 cited the cultural background questions as effective guidelines for training the ABA paraprofessional to work in multicultural settings (Table 7).

Table 7

*Feedback on Training Module 2—Question 4*

What aspects of Module 2 were most effective?	
Evaluator	Comments
1	Good explanation of becoming familiar with yourself first
2	Guidelines for the ABA tutor, specifically cultural background questions
3	The cultural guidelines

As a tool used to train paraprofessionals to provide culturally responsive treatment, Evaluator 1 noted that “more specific applications” of the material would have strengthened Module 2 (Table 8 & Table 9). This response was elaborated with a recommendation to teach these applications by using examples that can be examined during breakouts for group work. Evaluator 3 expressed that an explanation of how “direct teaching” is perceived by Native American families seemed to be lacking from Module 2 (Table 8). This evaluator also suggested that the module could be strengthened with an explanation on how the level of acculturation is to be assessed for individuals within a family by mental health professionals (Table 9).

Table 8

*Feedback on Training Module 2—Question 3*


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With regards to knowledge and skills needed to provide home based treatment in a culturally responsive manner, what information would you have like to have seen included in Module 2 which may have been lacking?

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Evaluator	Comments
1	More specific applications—examples for small group work
2	None
3	How “direct teaching” is viewed by Native American families

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Table 9

*Feedback on Training Module 2—Question 5*


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What suggestions do you have about how to improve the effectiveness of Module 2?

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Evaluator	Comments
1	More specific guidance with practice examples
2	None
3	Suggestions for how to assess the individual level of acculturation within a family

---

**Strengths and Weaknesses of Module 3**

Based on a scale from 1 to 5 with 1 signifying “not at all” and 5 “very much so,” all four respondents found the training resource to provide useful information for working



within Native American homes ( $M=4.67$ , Table 10) while being somewhat concise and easy to read ( $M=4.33$ , Table 10).

Table 10

*Feedback on Training Module 3—Question 1*

Evaluator	Usefulness	Readability
1	5	4
2	5	5
3	4	4

*Note.* 1 = not at all, 2 = not really, 3 = neutral, 4 = somewhat, 5 = very much so.

Evaluator 2 explained that the most effective training element of Module 3 is the presentation of the “impact of historical trauma” on Native American families (Table 11). “The balance of the four dimensions of each person and need for harmony amongst all 4” as well as the ways in which these values could influence the development of treatment goals were cited as an effective training element by Evaluator 3.

Table 11

*Feedback on Training Module 3—Question 4*

What aspects of Module 3 were most effective?	
Evaluator	Comments
1	Good introduction to NA issues
2	The impact of historical trauma
3	The balance of the four dimensions of each person and need for harmony amongst all 4 could influence treatment goals

Evaluator 1 noted that this particular Module could be improved by increasing the structure of the practice exercises (Table 13). Evaluator 3 would have liked to have seen a discussion on the situations in which teaching direct eye contact could be interpreted as offensive by Native American caregivers (Table 12). This evaluator suggested that the inclusion of an explanation of “how autism is viewed—is it influenced by the 4 dimensions (1 is too much, not enough, i.e. how does the imbalance manifest itself?)” be presented in Module 3 (Table 13). Evaluator 1 commented that although Module 3 provided a “good introduction to Native American issues,” (Table 11) the information presented could be in excess of the material to be taught in the course of a single day (Table 12).

Table 12

*Feedback on Training Module 3—Question 3*

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With regard to knowledge and skills needed to work in a culturally responsive manner with the Native American population, what information would you have like to have seen included in Module 3 that may have been lacking?	
<hr/>	
Evaluator	Comments
<hr/>	
1	A great deal of information for one day
2	None
3	Some information on how teaching direct eye contact could be interpreted as culturally offensive

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Table 13

*Feedback on Training Module 3—Question 5*

What suggestions do you have about how to improve the effectiveness of Module 3?	
Evaluator	Comments
1	More structure to practice exercises
2	None
3	How autism is viewed—is it influenced by the 4 dimensions (1 in too much, not enough, i.e. how does the imbalance manifest itself?)

**Recommendations for the Training Resource**

Based on a scale from 1 to 5 with 1 signifying “not at all” and 5 “very much so,” respondents rated the likelihood of recommending this training resource to ABA programs serving the Native American Autistic population as somewhat likely ( $M=4.33$ , Table 14). Evaluator 1 commented that he or she would be somewhat likely to recommend this training resource that he or she felt that the work was a “good project” (Table 14 & Table 15). Evaluator 2 indicated that he or she would definitely recommend this training resource and commented that he or she felt that “Module 3 was a thorough overview of Native American families” (Table 15). Evaluator 3 commented that the training resource provided a “really nice overview and synthesis of difficult information, emotionally and psychologically (Table 15).

All feedback supported the continued development of this training resource.

Table 14

*Recommendations on the Training Resource—Question 6*


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How likely would you be to recommend this manual to other mental health providers providing home based ABA services to the pediatric Native American population?

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Evaluator	Rating
1	4
2	5
3	4

---

*Note.* 1 = not at all, 2 = not really, 3 = neutral, 4 = somewhat, 5 = very much so.

Table 15

*Recommendations on the Training Resource—Question 7*


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Please provide any other comments or suggestions you have about the training resource.

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Evaluator	Comments
1	This is a good project!
2	Module 3 was a thorough overview of Native American families
3	Really nice overview and synthesis of difficult information, emotionally and psychologically.

---

## **Chapter 5: Discussion**

### **Summary and Overview of the Training Resource**

The objective of this project was to develop a culturally responsive training resource for clinical directors of Adaptive Behavioral Analysis (ABA) programs. This training resource is intended for use by clinical directors to prepare their paraprofessional tutors to work with autistic children in Native American homes. The resource strives to require that paraprofessionals receive cultural competency skills prior to entry into a client's home. This heavily culture-laden in home setting necessitates a high degree of cultural competency skills. This culture specific training expects paraprofessionals to begin by honestly reflecting and assessing their own cultural values and beliefs, then to acquire and compare knowledge of traditional Native American families with their own, prior to working within the Native American client's home.

A systematic search of pertinent peer-reviewed empirical sources in the areas of autism, paraprofessional training, and multicultural psychology were gathered in the development of the training resource. In order to determine that only the most pertinent material was included in the resource, triangulation of these resources were used. The completed manual is composed of three training modules, which are intended to be presented over the course of 3 days of instruction. The training is expected to be led by a licensed mental health professional who has undergone cultural competency education in the course of his or her own professional training. These licensed mental health clinicians, acting as ABA program coordinators, would utilize this training as an addendum to current, readily available ABA training manuals.

### **Evaluation of the Training Resource**

The training resource, *ABA in Native American Homes: A culturally -responsive training resource for paraprofessionals*, was reviewed and evaluated by three licensed mental health professionals using a response form created specifically for this project. The expert panel of licensed mental health professionals that evaluated the resource possesses both extensive experience working with Native American families, ABA technique, and theory as well as experience working with individuals diagnosed with an autism spectrum disorder.

### **Strengths of the Training Resource**

Overall, feedback on the resource was encouraging. The resource was evaluated to be a somewhat useful training tool that provided a good overview of cultural issues involved in providing ABA in Native American homes. An evaluator whom identifies as an active tribal member indicated that he or she would very likely recommend it to colleagues. The remaining two evaluators indicated that they were somewhat likely to recommend the use of the training resource. The expert panel offered support in the further development of the training resource stating it is a “good project,” and that it presented a “really nice overview and synthesis” of information that can be emotionally and psychologically difficult to process.

The resource satisfied the aim to increase awareness of cultural competency issues inherent in delivering in-home ABA treatment for the reduction of unwanted symptoms associated with autism. Unfortunately current training omits attention to cultural issues (Mandell & Novak, 2005). Awareness of the importance of understanding how culture can influence one’s view of diagnostic criteria and treatment selection is

beginning to gain attention in empirical literature (Bernier et al., 2010). The introduction in Module 1 was found to be successful in establishing the need for cultural competency training. As noted by the expert panel, the introduction to the manual was proficient in establishing a need for the resource and the first module successfully highlighted the notion that each and every caregiver involved can have his or her own distinct expectation of what home-based ABA treatment will be like on a daily basis. According to Kapp (2011), training teachers to compare and contrast cultural worldviews may result in more successful education for Navajo individuals diagnosed with autism. The first module was also able to emphasize important concepts such as variation in family expectations and the culture of developmental disability. Each caregiver can possess their own idea of how the child client will function following treatment. The Autism module established that a culture of autism and ABA tutoring exists and can have a major impact on conducting in-home treatment.

The cultural competence module was found to be useful in paraprofessional training as well as somewhat concise and easy to read. The cultural guidelines were noted to be an effective training tool. The guidelines were derived from the American Psychiatric Association's guidelines for Providers of Psychological Services to Ethnic, Linguistic, and Culturally Diverse Populations and adapted for applicability to paraprofessionals providing home based treatment (APA, 2011). Two of the three evaluators supported that the emphasis on understanding one's own cultural beliefs prior to working in a multicultural setting was effectively presented in the Module 2 training.

The final module specific to Native American families aspired to instruct paraprofessionals not only about the beliefs and values that are culturally relevant in

more traditional Native American homes, but also to dispel the myths paraprofessionals may possess about Native American people and their history. Historical trauma is emphasized, as it can have major implications in establishing rapport with caregivers and affect the treatment planning for the autistic child. Respondents noted that this module effectively taught the pervasive impact that a history of intergenerational trauma can have on Native American families. This module was also found to explain the importance of maintaining a sense of balance across the four sacred dimensions in order to achieve a healthy life. These cultural beliefs have a major impact on traditional Native American family expectations and in turn, should influence treatment planning as well as respectful working relationship with the caregivers.

In a list of recommendations for counseling interventions that meet the needs of Native American students, Mitchum (1989) found that non-Native American school counselors often misinterpreted student's non-verbal behavior. Minimal eye contact was interpreted as portraying embarrassment or withdrawal, as opposed to the Native American value of lowering one's gaze out of respect for one's elder. She explains that the lack of understanding Native American cultural values lead counselors to make false assumptions about the child's behavior and also resulted in treatment programs that run counter to Native American values. This type of misinterpretation was also cited as occurring in the assessment of Native American men in prison. Brant (1993) explained that culture bound non-verbal behavior was misinterpreted as depression, resistance and shyness by clinicians and paraprofessionals. Paraprofessional knowledge of Native American values and how they influence behavior is a vital factor in the development of a successful working relationship with the Native American family (Eldredge, 1993).



The training modules were arranged in this order with the hope to inspire the paraprofessional to stop and think about assumptions or reactions they may have in their interactions with clients and caregivers. With a better understanding of their own cultural values and an increased level of knowledge and skills specific to working with Native American families, a paraprofessional ABA tutor can enter a Native American home in a more professional manner. This type of culturally responsive critical reasoning can potentially improve treatment effectiveness and reduces the occurrence of cultural misunderstandings between tutors and caregivers, that diminish the therapeutic relationship (Brant, 1993).

### **Limitations and Recommendations**

Due to the small sample size of the expert panel and with only one participant identifying as belonging to a registered Native American tribe, at this time it is not possible to extrapolate the data beyond individual examples. Feedback gathered in this evaluation will however assist the author in further refinement of this training resource. Despite attending several Native American Behavioral health conferences across the United States, the author was only able to find two licensed mental health professional offering ABA services to Native American clients. At these conferences when inquiries were made regarding ABA tutoring in “Indian country,” behavioral health professionals were quick to respond that they did not know of anyone but that they were in desperate need of such services.

The limitations of the current training resource offers a myriad of opportunities for improvement. Some of the revisions will involve the inclusion of previously omitted information. As cited by one of the evaluators, providing an index could greatly improve

the portability of the training resource. A table of contents at the start of the manual could serve as an outline of topics to be discussed in the training presentation as well as serve as a resource for paraprofessionals to return to specific topics as needed. Further, the start of each module could include a topic specific outline. These outlines can be utilized in the form of a handout for paraprofessionals to take notes upon and to prepare for the day's lesson.

Two of the three evaluators noted that a more in-depth explanation of the variety of ABA approaches is needed to better prepare paraprofessionals for their work. The author omitted this elaboration because throughout the history of the development of treatment approaches for ASD, the field has been replete with acronyms for treatment approaches that when analyzed closely, present as variations of the discrete trial training utilized in ABA. These acronyms can be overwhelming; however, by leaving this information out, paraprofessionals can be wanting when caregivers turn to them for information about these teaching methods. It is indeed important that paraprofessionals be informed of the numerous treatments available to encourage the importance of understanding empirically supported approaches that can ensure the safety of the child with ASD and his or her caregivers. To make information on these treatment approaches less daunting, individual description, empirical support and references could be presented in the form of a table, formatted as a timeline. A column can be included which synthesizes the common processes of these treatment approaches to further equip the paraprofessional tutor with this knowledge.

Evaluator 3 was astute in raising important issues specifically related to working with Native American families that were left out of the training resource. One issue that

was not addressed in the resource involves the perception of autism among Native American families. This concept has been difficult to define. Early literature on traditional Native American perception of developmental disability presents great variation across tribes and is further complicated by varying degrees of acculturation. Some tribes such as the Navajo, did not have a word for disability prior to colonization (Kapp, 2011). Some tribes were found to believe that a child with a developmental disability represents a special gift from the Creator and others that the individual will simply grow to embody their predetermined place in the world as dictated by the Creator (Kapp, 2011). Interaction with this individual is seen as an opportunity to learn about finding balance across the four sacred directions. Other tribes found that giving birth to a child with a developmental disability was a punishment for parental misbehavior for living out of balance. Post colonization, some Native Americans felt that having a child with a developmental disability was a punishment for misdeeds such as excessive alcohol consumption (Connors & Donnellan, 1998; McCallion et al., 1997; McShane, 1988; Patterson, 1997).

Another issue omitted from the resource relates to the possible affect that gender differences can have on the expectations that Native American caregivers can have for their child's outcome level of functioning. Unfortunately the author was unable to find information in the literature specific to developmental disability and gender. This is an ideal practice exercise topic that can be processed in a break out group. The topic of gender also can include gender identity as this has been a topic of interest in the ASD literature (Mukaddes, 2002; Tissot, 2009). It has been the authors experience in working with Autism Spectrum Disorders that a great deal of anxiety can arise for caregivers and

paraprofessionals alike when a school aged client prefers activities and toys that are gender specific for the opposite sex. For example, an eight year-old male client diagnosed with ASD whom would like to dress as a princess for his birthday party can threaten a caregiver' or tutors' cultural beliefs, as well as potentially put the client in danger of bullying by peers. The caregivers and behavioral team must be comfortable discussing these complicated gender issues so that they do not miss the opportunity to teach societal norms, bullying and the clients' safety (Tissot, 2009).

A third area for consideration is the way in which Native Americans caregivers perceive the direct style of teaching inherent in ABA tutoring. Peer-reviewed journals have indicated that the direct teaching approach has been found to be effective with many Native American clients particularly if provided by a culturally competent therapist. A variety of cognitive behavioral programs have adapted the sacred circle and its four quadrants to develop culturally responsive treatments for substance abuse (Coyhis & Simonelli, 2005; Gone, 2011). There also exists support for the use of more humanistic but direct theoretically based approaches when working with Native American clients (Villanueva, Tonigan, & Miller, 2007). Unfortunately, information about how these various treatment approaches are perceived by caregivers when it is directed upon their children is not yet available. Traditionally, average developing Native American children are guided by means of more permissive approaches when learning life lessons and discipline from caregivers, which emphasizes learning through experience. The direct style of ABA teaching will definitely be at odds with this belief system (Red Horse, 1997). Some of the difficult behaviors associated with ASD such as self-injurious behaviors and inflexible adherence to schedules would invite Native American caregivers

to try new approaches to teaching. It would be helpful to remind paraprofessionals that not all families, Native American or otherwise will be comfortable with this style of treatment. It would also be imperative for cultural sensitivity to be used in treatment planning so as not to teach a client behavior that their family or clan would interpret as disrespectful.

The last culture specific topic that was noted as lacking from the resource is the teaching of direct “eye contact.” This is yet another controversial and useful topic for discussion among ABA paraprofessionals and the training facilitator. Empirical literature supports that in order to show respect to an elder member of a Native American tribe, one must lower his or her eyes so as to avoid direct eye contact (Eldredge, 1993). Some professionals working within the Native American community criticize “outsiders” for taking this lowered eyes behavior as a concrete rule. In truth, it is helpful for a non-Native American individual to understand the entire meaning and use of direct eye contact. For example, as Brant (1993) explains, sustained eye contact is considered offensive to the Mohawk tribe because it is used to initiate a physical altercation. It is a nonverbal behavior used to communicate aggression. Encouraging discussion on how the behavior is interpreted can encourage paraprofessionals to obtain a deeper understanding of this important non-verbal behavior as opposed to simply accepting it as a rule. Future revisions of the training resource can be strengthened by the inclusion of culture specific definitions of both verbal and non-verbal behaviors. The end goal is for paraprofessional tutors to be able to use their critical reasoning skills along with their newly acquired knowledge on traditional Native American beliefs to navigate culturally appropriate treatment for the client and their caregivers.

Due in part to tribal variation and sparse research, specific information on cultural concepts are not always easily accessed. However, this limited information can still be an effective point of discussion for the practice exercises at the end of the modules. The culture specific issues found to be lacking from the current training resource can readily be incorporated into future revisions of the resource. These topics can be used to discuss how one goes about assessing a client's cultural identity and level of acculturation. When studying how cultural values can influence the counseling relationship for Native Americans that are also deaf, Eldredge (1993) points out that to avoid the pit falls of stereotyping the client, an ongoing assessment of their level of acculturation must take place to make sure that treatment is consistent with their identity. Evaluator 1 requested more developed practice examples in the cultural competence and Native American families module to improve the training resource's overall effectiveness, assessing the level of acculturation can be practiced during break out sessions. For example, young trainees can be asked to observe their own non-verbal behavior as well as objectively gather information on their physical appearance. They can be asked to discuss what assumptions could be made about them and their level of acculturation based on this observation. They can also be asked what could be learned about them by walking in unannounced to their home.

As the author reflects upon the information that was omitted from the training resource, the responsibility of training future facilitators of this training program is raised. The skill set required to train future "trainers," convinces the author of the importance of first sharing all of the available cultural competency information and skills with future trainers. The trainees can then practice using critical reasoning to navigate the cultural

appropriate responses and treatment. The goal of training future facilitators is for them to independently master the culturally responsive skill set themselves prior to training paraprofessional tutors. This can be accomplished when the skills have been shared and utilized with the help of more developed group exercises.

A Respondent noted that the training could be more effective if the last module was presented over the course of two days instead of one. There is simply too much information on Native American families to be presented in the course of a single day of training. Unfortunately, because culturally responsive training is not offered in the training of paraprofessional ABA tutors, the author was over cautious about the portability of a training that lasted more than three days. Current training of ABA tutors can at times be conducted without compensation to the trainee and many times simply involves having a prospective tutor “overlap” and observe a more experienced tutor work with a client. There is no question that an additional day to present information on Native American families would be incredibly useful, however program directors may not recognize that the need for this additional training would outweigh their fiscal considerations. A possible solution to maximizing the portability of the resource would be to allow clinic directors to determine which of the modules they would like emphasized. The training can then be made to fit the needs of each ABA clinic it serves.

Not only is there a lengthy amount of information to be presented in module 3, but also the content can evoke a strong emotional reaction from trainees. Even within the community of Native American behavioral health professionals, this history lesson and its ramifications can potentially evoke strong emotions not only related to the gravity of the information but it can also activate painful memories from one’s own trauma

experiences. It is important to point out that non-Native American tutors can experience a guild reaction to the material. As a result of these reactions, at Native American behavioral health conferences where this material is routinely presented, conference organizers regularly offer opportunities for healing “the helpers.” Conference attendees are warned of possible reactions to the material. Medicine people, healing circles, sweats or other healing ceremonies traditional in Native American heritage are also routinely made available to attendees. Due to the magnitude of information presented in this module, it is advisable, as suggested by the expert panel, to extend this last training module for an additional day of training. The author believes that similar advisory and psychological support should be offered to paraprofessional trainees in the form of counseling referral when presenting the last module.

As the author reflects upon the project, several important topics such as cultural identity related to gender issues, psychopharmacology, vitamin supplements, and comorbid mental illnesses have been overlooked. In Module 1 a discussion of real-life treatment outcomes can be conducted through use of the practice exercises to begin a dialogue about what it is like to live with an ASD for the diagnosed individual as well as for caregivers and siblings. This ice breaking exercise can serve to dispel the myths presented in the media and prepare trainees for the format of the training. An additional table reflecting treatments that have not received support for their effectiveness or use could also assist in providing information on alternative therapy approaches that a paraprofessional might encounter while providing ABA treatment in the home. Module 2 and 3 can be improved with more detailed discussions and group activities so that new



skills can be put into practice and mastered. Despite these limitations, the resource has the potential for great improvement.

This project aims to begin a dialogue about the way in which cultural concerns can arise in home-based ABA programs. By further developing break-outs and the two-part third module, culturally responsive approaches can be tailored to a great variety of marginalized cultures currently utilizing home-based ABA treatment.

### **Reflections on Process**

Developing a training resource brought forth unexpected considerations for the author. It quickly became clear that offering straightforward information on cultural differences and similarities would not be sufficient in preparing individuals to make the complex decisions required in providing culturally sensitive treatment. This information would serve as the first step in training awareness of cultural issues, however critical reasoning is required to understand how to conduct culturally-responsive treatment. Trainees are being expected to conduct ABA services with the understanding that there is major variability in cultural identification on a macro and micro level. Assessment of an individual's level of acculturation is an ongoing process as culture is an internal and external process. A great deal of flexibility is expected of these behavioral teams in order to adapt to the specific needs of the client and their family.

One must consider that many paraprofessional tutors have completed high school and are beginning secondary college education. Behavioral tutors tend to be young. It has been the authors' experience that some of these prospective behavioral tutors do not possess prior work experience. Although they may be very well meaning in their approach to ABA work, they may lack the interpersonal boundaries and professionalism

gained through work experience. This equates to less experience navigating difficult situations, many of which are complicated when working in someone's home. It is not unusual to hear accounts of caregivers asking behavioral tutors out on dates. Many tutors are asked to terminate their employment with ABA programs so they can work privately for caregivers. These families will use the lure of higher pay to encourage tutors to make this change and as a result some ABA programs are requiring their tutors to sign contracts prohibiting this from occurring.

In general, producing this training resource has been a fascinating process. Collecting and presenting information on the discrimination and abuse faced by indigenous Americans was in itself a stressful and traumatic process. The author found herself in need of emotional support following the review of first hand accounts of rape and torture inflicted upon school aged Native American children in oppressive boarding schools. Relief was found in the post-traumatic literature and liberation psychology discourse. Further, the incredibly strong network of native and non-native mental health professionals working in this field offered continued support and encouragement in completing this project. These professionals embodied the healing path transcending the affects of historical trauma that empowers the communities that they serve as well as the author.

### **Plan for Future Development of the Training Resource**

Once modification of the training resource has been completed, based on the recommendations made by the expert panel, the next step would be for the author to present the edited training resource to ABA program coordinators currently working in Native American homes. The author could lead the training in vivo while administering

pre- and post-evaluations assessing the perceived usefulness of the information presented as well as obtaining suggestions for future editions of the training. Pre- and post-evaluations of the training resource can be utilized to further revise the training program for future publication.

With permission from tribal leaders, a caregiver needs assessment could serve as a useful training tool as part of this training resource. With permission, caregivers could be video taped sharing their concerns with ABA treatment and staff. Watching the non-verbal behavior of the caregiver speaking about perceived violations by ABA staff can be more impactful than solely reading their quotations. This can ensure that caregiver concerns are addressed in the resource and it also allows for a powerful training instrument.

The concept for a culturally responsive training in ABA was well received by the Native American behavioral health community. As noted in chapter 3, a colleague contacted by a potential participant, has offered her own staff to be trained for a pilot study should the author be interested in further development of the training.

## **Conclusion**

Expert feedback on the training resource was encouraging. As with many indigenous populations around the world, Native Americans are in the process of rebuilding and strengthening their communities following years of suffering the effects of forced colonization and the resulting historical trauma (Duran, Firehammer, & Gonzalez, 2008). In order to respect the healing path of Native American communities, it is of utmost importance for coordinators of Adaptive Behavioral Analysis programs to responsibly equip their teams of paraprofessionals with the cultural education they

require before entering Native American homes. Given the healing process and path that the Native American community are currently engaged, clinicians responsible for training paraprofessionals to provide ABA services need to prepare their staff with the necessary tools to conduct culturally responsive treatment. Although it is common for paraprofessional tutors to believe that the focus of their duties lie in the behavioral style tutoring of the autistic child, their interactions with caregivers are to be valued and respected as an integral factor in the success of the ABA treatment. Armed with adequate training, paraprofessionals can conduct ABA tutoring while making respectful space for the community to continue its healing process.

This project attempts to create a dialogue about respectful service delivery, which serves to improve interactions between professionals and families that not only advances the child's cognitive and behavioral gains, but also honors the beliefs of the caregivers. Culturally responsive work is an evolving process; this scholarship attempts to contribute to a discourse about the importance of cultural competency skills in ABA programs for individuals diagnosed with autistic spectrum disorder.

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## APPENDIX A

### Outline/Syllabus of Presentation

## Outline/Syllabus of Presentation

### I. Chapter 1

#### a. Introduction

##### i. Statement of Problem

##### ii. Purpose of the Project

#### b. Literature Review

##### i. Native American History

##### a. The Historical Relationship between Public Services and Native American People

##### 2. Providing Mental Health Services to Native American Families

##### 3. Legal History

##### 4. Historical Trauma

##### a. Boarding Schools

##### 5. Native American Communities

##### 6. Native American Mental Health Services Overview

##### 7. Traditional Native American Values

##### a. Native American World View

##### i. Native American Families

##### b. Native American Spirituality

##### c. Native American Identity Then and Now

##### 8. Cultural Strengths versus a deficit Orientation to Treatment



9. Current Theoretical Models for Treatment in the Native  
American Community

ii. Cultural Competence

1. The Culture of Providing In-home Services

a. Bicultural Competence

b. Entry into Native American Homes

iii. Overview of the Autism Spectrum Disorder Diagnostic Criteria

1. Behavioral Profile

2. Prevalence

3. Treatment

a. Applied Behavioral Analysis

i. Empirical Support for Applied Behavioral  
Analysis

4. Raising a Child with an Autism Spectrum Disorder

c. Questions Guiding the Study

II. Chapter 2

a. Method

i. Objectives of the Scholarship

1. Overview

2. Rationale

ii. Steps for the Development of the resource

iii. Practical Contribution of the Study

1. Summary and Organization

- iv. Resource Outline

- v. Resource Evaluation

- b. Participants

- c. Procedure

- d. Summary

- III. Chapter 3

- a. Resource Manual Evaluation

- b. Resource Manual based on Evaluation Feedback

## APPENDIX B

### Introduction Letter

### Introduction Letter

Hello, My name is Belinda Najera, we met at the July 27–29, 2010 Indian Health Service/Bureau of Indian Affairs (HIS/BIA) National Behavioral Health Conference held in Sacramento, California. At the BIA/HIS first conference, the premiere presentation of “Approaches to Autism in American Indian and Alaska Native Communities” was offered and during this lecture, a networking list was passed around to individuals interested in the topic and also in continued communication between professionals. I am sending this e-mail to individuals on the aforementioned networking e-mail list. I am a doctoral candidate in clinical psychology at Pepperdine University in Los Angeles and I had asked if you would be interested in learning more about my doctoral research project.

Participation would be completely voluntary and would consist of review a training resource developed for use in training paraprofessionals to provide home based Applied Behavioral Analysis to Autistic children in Native American homes and then to provide feedback based on your experience in the field.

Guidelines for participation include: a minimum of three years experience working as a licensed behavioral or mental health working with Native American families, familiarity with Applied Behavioral Analysis, and familiarity with Autistic Spectrum Disorders.

If you are interested in participating in this study or would like more information, please contact me by replying to this e-mail. You may also telephone at [REDACTED]. If you meet the criteria and decide to participate a consent form, the training resource, evaluation form and two pre-paid return envelopes will be mailed to you. Participation in this study is completely voluntary and you would be free to withdraw at any time.

Sincerely,

Belinda Najera, M.A.

## APPENDIX C

### Cover Letter for Informed Consent and Evaluation Form

Dear Mental Health Professional,

Thank you for your interest in participating in this study. The feedback that you will provide will assist in the development of a culturally responsive training resource for the training of paraprofessionals preparing to work with Native American families of children diagnosed with Autism Spectrum Disorders.

Provided for you in this packet:

1. 2 copies of the Informed Consent, one to keep for your records and one to return in the attached pre-paid self-addressed letter size envelope
2. a copy of the resource titled “ABA in Native American Homes: A culturally-responsive training,” and
3. an evaluation form attached to a large pre-paid self-addressed stamped envelope

It will take approximately 30 minutes to review the resource and 10-15 minutes to write your responses on the evaluation form. The evaluation form does not request personal or information that can be used to determine your identity, however it does ask for you to share your opinion. You will not be able to be identified from responses on your evaluation form and your signed Informed Consent form will be sent and received separately from your evaluation to ensure your confidentiality. Your participation in this study is completely voluntary, you may refuse to participate or complete the evaluation at your own discretion.

If you wish to participate in the study, please read and sign the informed consent. My contact information is provided should you have any questions or concerns. The

Consent can be returned immediately in the letter size envelope. Upon completion of the Evaluation form, return it in the large self-addressed stamped envelope.

My sincerest thanks for your support, feel free to contact me at any time at [REDACTED]  
or via e-mail at [REDACTED].

Best wishes,

Belinda Najera, M.A.

Psy.D. Candidate

Graduate School of Education and Psychology

Pepperdine University

## APPENDIX D

### IRB Compliance Consent Form for Mental Health Specialists



Evaluator Informed Consent for Review of a Culturally-Responsive ABA Training  
Resource for Paraprofessionals

I authorize Belinda Najera, M.A., a clinical psychology doctoral candidate under the supervision of Dr. Tomas Martinez at Pepperdine University's, Graduate School of Education and Psychology, to include me in the research project titled, "ABA in Native American Homes: A Culturally-Responsive Training Resource for Paraprofessionals." I understand that Mrs. Najera is completing this study to meet doctoral dissertation requirements.

I understand that my participation in this study is strictly voluntary and that I am free to withdraw at any time.

I have been asked to review and evaluate a training resource that is intended for use in the training of paraprofessionals to provide Applied Behavioral Analysis services for Native American children diagnosed with an Autism Spectrum Disorder. My participation was requested because I am a behavioral or mental health professional who currently works with Native American families. The study will require that I read the working draft of the training resource and provide feedback using the evaluation form provided by the researcher. Following the completion of the evaluation form, I will return it to the investigator using the pre-paid envelope addressed to Belinda Najera, M.A.

I understand that all of the feedback and information that will be collected in this study will be confidential and stored in locked filing cabinets. The Informed Consent Forms will be kept in a separate locked filing cabinet than the evaluation feedback Forms. All data and research materials will be destroyed and disposed of following a five-year storage period. It is my understanding that feedback provided may be published

or presented to a professional audience, however any identifying information will remain confidential.

This study poses no more than minimal risk. The minimal risks involved in my participation include the amount of time required to read the resource then to provide feedback as well as the possibility of experiencing discomfort while reflecting on the difficulty Native American families with a child diagnosed with an Autism Spectrum Disorder face as a result of socio-economic status or due to historical trauma. Fatigue or boredom may occur as a result of reading the training resource and completing the feedback surveys which include a series of Likert scale items as well as an open-ended question. The investigator has suggested that the review and feedback occur when it most convenient for me to do so and that it is acceptable to take breaks if necessary. I understand that I can withdraw from the study or refuse to answer specific questions at any time without bias or prejudice.

It has been made clear that I will not directly benefit from my participation in this study, but that my participation has the potential to expand the dialogue on culturally responsive treatment delivery to Native American families with a child diagnosed with an Autism Spectrum Disorder. I will not be compensated, financial or otherwise for my participation in this study. It is my right to refuse to provide feedback to any of the questions provided and I may withdraw from the study at any time without consequence.

I understand that should I have any questions with regard to the study procedures that I can directly contact Belinda Najera, M.A. at [REDACTED] or Tomas Martinez, Ph.D., Dissertation Chairperson at Pepperdine University, Graduate School of Education

and Psychology, 6100 Center Drive, Los Angeles, CA 90045, (310) 506-4350 to answer any of my questions.

If I have concerns or questions about human subjects' issues in this study, I can contact Yuying Tsong, Ph.D., Chairperson, Graduate and Professional IRB at Pepperdine University Graduate School of Education and Psychology, 310-568-5768, 6100 Center Drive, Los Angeles, CA 90045, [Yuying.Tsong@pepperdine.edu](mailto:Yuying.Tsong@pepperdine.edu).

I have thoroughly read this form and to my satisfaction understand the statements contained herein. In signing this form I agree to participate in the study on ABA in Native American Homes: A Culturally-Responsive Training Resource for Paraprofessionals and acknowledge that I have received a copy of this form.

---

Participant's Name

---

Participant's Signature

---

Date

## APPENDIX E

### Resource Evaluation Form

## Resource Evaluation Form

Code \_\_\_\_\_

Number of years working with the Native American population \_\_\_\_\_

Number of years working with Autism Spectrum Disorders \_\_\_\_\_

Licensure/credentials \_\_\_\_\_

## MODULE 1

On a scale of 1-5 where 1 is not at all and 5 is very much so:

1. Do you feel that this training module provides useful information for use with ABA paraprofessionals preparing to provide home based treatment to families of a child diagnosed with an Autism Spectrum Disorder?

1      2      3      4      5

2. Was the module concise and easy to understand?

1      2      3      4      5

3. With regards to knowledge and skills needed to work in a culturally responsive manner with the individuals diagnosed with an Autism Spectrum Disorder, what information would you have liked to have seen included in Module 1 which may have been lacking?

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4. What aspects of Module 1 were most effective?

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5. What suggestions do you have about how to improve the effectiveness of Module 1?

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## MODULE 2

On a scale of 1-5 where 1 is not at all and 5 is very much so:

1. Do you feel that this training module provides useful information for use with ABA paraprofessionals preparing to provide culturally competent home based treatment?

1      2      3      4      5

2. Was the module concise and easy to understand?

1      2      3      4      5

3. With regards to knowledge and skills needed to provide home based treatment in a culturally responsive manner, what information would you have liked to have seen included in Module 2 which may have been lacking?

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4. What aspects of Module 2 were most effective?

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5. What suggestions do you have about how to improve the effectiveness of Module 2?

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### MODULE 3

On a scale of 1-5 where 1 is not at all and 5 is very much so:

1. Do you feel that this training module provides useful information for use with ABA paraprofessionals preparing to work in Native American Homes?

1      2      3      4      5

2. Was the module concise and easy to understand?

1      2      3      4      5

3. With regards to knowledge and skills needed to work in a culturally responsive manner with the Native American population, what information would you have liked to have seen included in Module 3 which may have been lacking?

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4. What aspects of Module 3 were most effective?

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5. What suggestions do you have about how to improve the effectiveness of Module 3?

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6. How likely would you be to recommend this manual to other mental health providers providing home based ABA services to the pediatric Native American population?

1      2      3      4      5

7. Please provide any other comments or suggestions you have about the training resource.

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Thank you so much for your time and valuable input in reviewing this training resource.



APPENDIX F  
Training Resource



# ABA in Native American Homes:

## A Culturally-Responsive Training for Paraprofessionals

Belinda Najera, M.A., Doctoral Candidate  
dbsabzb@mac.com  
Pepperdine University

**ABA in Native American Homes: A Culturally-Responsive Training for  
Paraprofessionals**

Belinda Najera, M.A.

## **Overview of the Training Manual**

Information will be organized into three training modules. Group exercises are presented at the end of each module and are intended to encourage the paraprofessional in training to carefully consider their own cultural beliefs and values. The training is intended to be lead by a mental health specialist who has received training in the area of cultural competency required in their professional course work. The training is divided into three sessions to be presented on three separate days. The resource will begin with an overview of the Autism Spectrum of disorders and associated cultural issues.

Cultural competence will be discussed during the second module. Analysis of one's own cultural beliefs and values will be emphasized. Topics such as one's social status, gender, sexual orientation and access to resources will be covered. Activities in which trainees are expected to consider their own beliefs in the area of child rearing, family organization and developmental disabilities will be presented. Understanding the power differential present in the helping profession and how the behavioral tutor is perceived dependent on the client's culture will be discussed. Western beliefs and the associated interpretations about the behavior of other cultures will be discussed.

The final module of the training resource will focus on skills and knowledge building with regards to understanding levels of acculturation and Native American culture. Trainees will be presented with information about Native American cultural beliefs and values stressing the variation in the degree of acculturation as well as how beliefs can also be blended (i.e. folk tales and Christianity). Historical trauma (HT)

followed by open-ended questions about the ways in which this may affect therapy and the perception of health care providers are a key component of this last module.

Trainees will be given the opportunity to discuss their own experience in regards to working with clients from a culture different from their own, and to discuss ways in which any problematic situations were resolved. Trainees will be asked to discuss how they expect culture to play a part in their work as an ABA tutor, illuminating that they will not only be interacting with the child with ASD but also with all of the individuals within the family network. They will be presented with the concept of using Adaptive Behavioral Analysis with Native American Children with ASD, but utilizing a more Existential approach with family/caregivers. Although trainees will be encouraged to present questions throughout the training, any remaining questions can be discussed prior to the close of each training module.

Within the field of psychology, Euro-American mental health treatment approaches have been adapted to fit the rest of the North American populous, including marginalized populations (Huey & Polo, 2008). When working with these populations, clinicians are ethically bound to take measures to ensure ethical treatment. These actions include using appropriate language and educating themselves about their clients' culture of origin to ensure culturally relevant treatment (American Psychiatric Association [APA], 2000). A number of peer-reviewed articles have been published in the topic area of cultural competency. They highlight the ways in which the differential of power held by individuals in helping professions are further complicated when these professionals engage in work with individuals from a culture different than their own (Cole, 2008; McGoldrick, Giordano, & Garcia-Preto, 2005; Rogers-Sirin & Sirin, 2009; Summers &

Jones, 2004). These professionals have chosen their career with the goal to utilize their knowledge to assist their clients in crisis. In order to provide proficient treatment, a clinician must establish rapport, making cultural competency of paramount importance. Professionals with the best intentions of providing culturally sensitive treatment for clients from a different cultural background can find themselves struggling to establish a rapport and meet their clients' individual needs (Cole, 2008).

The first and most important step toward providing culturally relevant treatment must begin with therapists making an effort to develop a clear understanding of their own cultural identity (McGoldrick, Giordano, & Garcia-Preto, 2005). Besides having the professional responsibility to be culturally competent, mental health practitioners have the added challenge of working with a variety of counseling theories and approaches that have not necessarily been developed with an individual's culture, gender and/or sexual orientation as a primary focus (Gallardo, Johnson, Parham, & Carter, 2009; LaFromboise & Rowe, 1983). Today, although efforts have been made to provide culturally responsive treatments for diverse populations, many of the existing approaches continue to lack adequate research to support their efficacy (Huey & Polo, 2008).

Culturally competent counselors must take responsibility for the limitations present in their chosen counseling approach and supplement their theoretical knowledge base with information that will enable them to best serve their clients. As outlined by the DSM-IV-TR, when developing a cultural formulation, a clinician will consider the client's culture or origin, level of identification with that culture, how their cultural context influences how distress and troubling symptoms are expressed, and how the therapeutic relationship may be affected by their cultural differences. The training of

culturally competent therapists generally holds that clinicians must be aware of their own ethnic identities and strive to understand and respect the value system of their clients (McGoldrick et al., 2005). In the field of developmental disability, this balance is further complicated by the frequent use of paraprofessionals.

Paraprofessionals whom work as behavioral tutors with individuals diagnosed with a developmental disability are not required to possess proficiency in cultural issues of any form. To complicate matters, these individuals are commonly referred to as “behavioral therapists” although many possess a minimum of a high school degree. Without the training of a therapist, they are expected to conduct behavioral services within the client’s home. Supervision by an individual with a minimum of a master’s degree-level mental health professional is provided on a monthly basis to these paraprofessionals.

Current training for Adaptive Behavioral Analysis (ABA) tutors excludes preparation for working in a culturally responsive manner and this is essential when working with the Native American population (Mutchler, Baker, & Lee, 2007; Zions et al., 2003). ABA training also excludes preparing paraprofessional tutors for providing behavioral services in the very personal and cultural laden confines of the client’s home. The goal of this training is to improve the standard of training provided for ABA tutors in order to serve the client and their caregivers more effectively.

## Module 1

### Autism Spectrum Disorder

#### Chapter 1: Pervasive Developmental Disorders

The term Pervasive Developmental disorders is used to describe five sub-categories of the pervasive developmental disorders, which include (a) autistic disorder, (b) childhood degenerative disorder, (c) Asperger's disorder, (d) Rett's syndrome, and (e) pervasive developmental disorder not otherwise specified (Buitelaar, Van der Gaag, Klin, & Volkmar, 1999; Wing & Gould, 1979; Szatmari, 2000). In anticipation of the 2013 publication of a new edition of the *Diagnostic and Statistical Manual*, it has been proposed that the diagnosis of Asperger's disorder will be subsumed into the Autistic disorder category.

Autism is a pervasive developmental disability, classified in the *Diagnostic and Statistical Manual IV-TR* (DSM-IV-TR), which tends to be diagnosed after age two (APA, 2000). Based on personal experience following 19 years, working with individuals diagnosed with an ASD, referrals for diagnosis tend to occur at this age as parents notice not only that their child has not reached developmental milestones for language, but also that parents note the way in which social skills are lacking as compared to toddlers of similar age. Their child does not attempt to share experiences with by motioning or pointing at novel stimuli, nor do they bring items they find interesting to share with their parent or caregiver. Autism impacts development in the areas of social and communication ability (APA, 2000). According to the Centers for Disease Control and



Prevention, approximately 34 in 10,000 children ages three to 10 years of age have a form of ASD (Centers for Disease Control and Prevention [CDC], 2004).

### **Overview of Autism Spectrum Disorders**

The Autism spectrum disorders are a well publicized, although not necessarily well understood developmental impairment. The spectrum includes a range of functioning that begins at the lower end of the spectrum with acute language and social impairment, up to the slightly improved functioning Autism and finally less impairment in Asperger's Syndrome. Autism is a neurodevelopment disorder with early childhood onset (APA, 2000; Moldin & Rubenstein, 2006; Wing, 1993). Specific symptoms of autistic disorder, as outlined in the DSM-IV-TR, are (a) delayed and disordered language development, (b) impaired social interaction, (c) repetitive and/or stereotyped behavior, and (d) often islands of remarkable knowledge sets despite other cognitive impairment (APA, 2000). Children diagnosed with Autism may also exhibit aberrant or aggressive behaviors, such as screaming, hitting, biting, and repeatedly lining up objects (Sigafos, 2000; Murphy et al., 2005).

Individuals diagnosed with ASD present with social impairment that ranges from mild to more profound impairment. It must not be assumed that this impairment means that a desire for social contact is lacking. Many individuals with High-functioning Autism and Asperger's Syndrome have communicated their desire to make friends and their frustration with their lack of ability to do so (Church, Alisanski & Amanullah, 2000; Myles & Simpson, 2002). The Autism spectrum involves a "triad of impairment" (APA, 2000; Wing, Gould, & Gillberg, 2011). This triad includes difficulty with (a.) social

interactions, (b.) social communication impairment and (c.) restricted areas of interest or excessive and repetitive behaviors. Individuals with ASD exhibit impairment in social interactions throughout the entire course of their life (Beadle-Brown, Murphy, & Wing, 2006; Stone, Baron-Cohen, & Knight, 1998). Interactions with others are further complicated not only by unusual verbal skills but also by their inability to interpret and appropriately respond to nonverbal communication (APA, 2000). Individuals with autism may understand concrete concepts and simple directions but will struggle when expected to comprehend the nuances of language that are utilized to convey irony, humor, or poetry (APA, 2000; Bigam, 2008).

Autistic individuals tend to possess restricted interests and/or repetitive proprioceptive behaviors. I have witnessed restricted interests that include an almost obsessional focus on trains, numbers, fabric texture, items of clothing and sport related statistics. Repetitive behaviors can include rocking, sideways eye gaze, hand flapping and a variety of self-injurious behaviors, particularly when the individual is experiencing frustration. Individuals diagnosed with low functioning ASD explain that a great deal of frustration is felt when interacting with the “normie” or “neurotypical” (normal) population. Many individuals maintain a strict routine and will exhibit serious distress or violent behavior if the routine is altered (APA, 2000). Individuals with ASD have reported that hypersensitivity to auditory and or visual stimulation can excite them resulting in repetitive self-stimulatory behaviors or overwhelm them to the point of self-abusive behavior.

# Autistic Disorder



6 or more items, at least 2 from A

<b>A) Marked impairment in social interaction</b>	<b>B) Impairment in communication</b>	<b>C) Restricted, repetitive and stereotyped patterns of behavior</b>
<ul style="list-style-type: none"> <li>• Non-verbal behavior to facilitate social</li> <li>• Sharing of enjoyment, interests</li> <li>• Social or emotional reciprocity – lack of social play or games, preference for solitary activities, interacts with others as if they are objects</li> <li>• Lack of varied make believe play, social interaction or social imitative play appropriate to developmental level</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of speech or delay, not accompanied by attempt to compensate thru alt modes</li> <li>• When speech is present, unable to initiate or sustain a conversation</li> <li>• Stereotyped and repetitive use of language or idiosyncratic language</li> </ul>	<ul style="list-style-type: none"> <li>• All encompassing preoccupation with something which is abnormal in intensity or focus</li> <li>• Inflexible adherence to nonfunctional routines or rituals</li> <li>• Stereotyped or repetitive motor mannerisms (hand or finger flapping, complex whole-body movements)               <ul style="list-style-type: none"> <li>• Persistent preoccupation with parts of object</li> </ul> </li> </ul>

## **Treatment**

There are a multitude of treatment approaches available for the treatment of symptoms associated with autism, including vitamin therapy, elimination diets, facilitative communication, and speech therapy; however, there is currently no known scientifically supported cure for autistic disorders, symptoms are lifelong (APA, 2000). The treatment most cited in the literature as showing empirical evidence for improving behavioral and cognitive symptoms associated with ASD is intensive adaptive behavioral analysis (ABA), also referred to as applied behavioral analysis or discrete trial training (Huber & Zivalich, 2004; Lovaas, 1987). In an ABA program, children are taught a variety of skills via discrete operant training. General academic, social and daily living skills are taught using a systematic process utilizing external positive reinforcement to increase desirable behavior in a one-on-one environment. Once individuals can successfully perform a desired task independently, the skill is generalized in the natural environment. The overriding philosophy of this treatment approach is to create a situation where an individual can succeed in achieving a skill through error free trials. Encouragement is offered through external reinforcement since internal reinforcement may not be intrinsically motivating (Huber & Zivalich, 2004). The experience of success is increased by breaking a more difficult task into smaller, easier to accomplish parts. Punishment is not used. Through the careful and consistent use of ABA programs specifically designed for an individual with symptoms associated with autism, individuals can be capable of achieving cognitive restructuring that will enable them to behave with increased developmentally appropriate social interest (Huber & Zivalich, 2004).

**Critical factors in ABA treatment of childhood Autism**

- Structured, consistent behavioral teaching
- Parental involvement
- Treatment at an early age
- Intensive intervention
- Focus on generalization of skills to a variety of settings

**Applied Behavioral Analysis**

Although there is no clearly documented cure for autism, research suggests that the problematic symptoms associated with ASD can be managed effectively using comprehensive behavioral and educational approaches (Kabot, Masi, & Segal 2003; Wing, 1997). Wing (1997) asserted that the most effective way to help children with an ASD is through structured education that is designed to maximize their abilities while minimizing their behavioral disturbances. Furthermore, it is important to provide parents with sufficient information and guidance to facilitate an organized, predictable environment at home for the child. When an individual with ASD is no longer school age, individuals who are not able to live independently require ongoing accommodation, occupation, and leisure activities tailored to their special needs (Wing, 1997).

Lovaas (1987) was the first to develop systematic and comprehensive behavioral intervention programs for children with autism. The basic tenet of behavioral analytic intervention is to deconstruct and organize the behavioral symptoms of autism into specifically defined skill domains. Thus, the goal with ABA is to reduce the maladaptive

behavioral excesses while increasing the social and communicative deficits. More specifically, the treatment protocol established by Lovaas (1987) in the Young Autism Project (YAP) relied on discrete trial discrimination. Receptive skills beginning with compliance, for example simple commands such as “sit down,” “look at me,” and “put here” are practiced with a behavioral tutor throughout all of the child’s waking hours. Aggressive and self-stimulatory behaviors were extinguished by: ignoring the behavior, punishing the behavior using a “time out,” or redirect the child to engage in alternative behaviors associated with a differential reinforcement.

## **Chapter 2: Working with families, who is the client?**

It is not uncommon for behavioral tutors to focus on the child with Autism as the sole focus and client. Since parent training and consistent teaching are major components of an effective ABA program, it is important to understand that the Autistic child’s network of caregivers are an integral factor in the client’s functioning and should be approached with the same respect given to the client. Some families may be accustomed to having people providing services in their home and some may be quite distrustful of “strangers” coming into their home. In households in which individuals are used to a staff of nanny’s, maids, chefs and dog walkers, the ABA tutor can be treated as another member of “the help.” Depending on the family’s prior exposure and cultural beliefs, entering a client’s home brings with it a variety of pitfalls and/or opportunity for misunderstandings. In a family with less exposure to such services, the ABA tutor can be seen as a stranger, doctor, or new member of their family. They will look to you as a specialist, behavioral tutors are asked to predict the child’s outcome, to explain new

“cure of the month” treatments, asked to compare how their child is progressing to other children with ASD whom the tutor has worked. Some caregivers will respectfully refer to the behavioral tutor as the doctor.

Paraprofessionals will find themselves exposed to the clients’ lifestyles, the resources available to them, their religious and political affiliations, and possibly family chaos and/or marital discord (Schacht, Tafoya, & Mirabla, 1989). The author has witnessed divorce, family violence, offered business opportunities, and on occasion been asked out on dates by caregivers while attempting to tutor a child diagnosed with an ASD.

### **Raising a Child with an Autism Spectrum Disorder**

The task of parenting a typically developing child can certainly be a stressful task; however parenting a child with an ASD can exponentially increase one’s stress load. In Poland, Dabrowska and Pisula (2010) investigated parents raising a child diagnosed with a developmental disability: ASD versus Down’s Syndrome. They found that parenting a child with Autism was rated as more stressful than raising a child with Down’s syndrome. As a result of the increased stress, parent support is encouraged as an important element of the treatment program (Osborne & Reed, 2010).

In addition to the burden of having a child who is more difficult to raise, another stress for parents of an individual diagnosed with autism is that, because it is a pervasive disorder, caregivers must navigate a lifetime of therapies and or assistive living for the entire course of the individual’s life. These therapies can include a multitude of professionals, advocates, lawyers, visiting one’s home, frequent interaction with medical

and mental health professionals and the bi-annual individualized educational program meetings (IEP's) associated with their school district. Moldin and Rubenstein (2006) estimated that such therapies can cost up to \$3.2 million per person diagnosed with autism over the individual's lifetime.

Many parents report that they must work through a mourning period following their child's diagnosis prior to achieving a state of acceptance of their child's limitations. At that point, caregivers can finally develop realistic expectations for their own and their child's future (Bilgin & Kucuk, 2010). To make matters worse, some families have been to several mental health professionals and received a variety of diagnosis that focus on specific elements of the child's disability before they are given the ASD diagnosis (Wilder, Dyches, Obiakor, & Algozzine, 2004). Paraprofessionals need preparation for the types of stress that these families have experienced prior to entering their home as a behavioral tutor.

### **Chapter 3: Cultural Issues involved in Treating Autism Spectrum Disorders**

Although current research on multicultural issues in ASD is limited, investigators across the world are beginning to question whether current treatment approaches are serving diverse populations effectively (Bernier, Mao, & Yen, 2010; Kapp, 2011). Language barriers and communication style when obtaining a diagnosis, advocating for their child, and for engaging in parent training, are cited as posing the greatest difficulty for minority families. Interpretation of behaviors associated with ASD can be affected by the individual's cultural lens. For example, Navajo caregivers did not report self-



stimulatory behaviors as being an area of concern whereas more westernized families may indicate it as a major issue to address (Connors & Donnellan, 1998).

When diagnosing a mental health problem, professionals must determine whether the presenting symptoms and behaviors are within mainstream, culturally acceptable norms, and whether it causes distress and disability to the individual (Levin & Schlozman, 2006). In the Netherlands, Begeer, El Bouk, Boussaid, Terwogt, & Koot, (2009) presented 82 pediatricians with six vignettes that differed in ethnic background and every two included one to three autism related features. A bias in spontaneous clinical judgment was found resulting in an under diagnosis for ethnic minorities. This under diagnosis was eliminated when explicit instructions to rate the likelihood that the diagnosis was associated with an ASD was given. Investigators also found that ASD children from ethnic minorities were underrepresented in the populations of their three major mental health institutions specializing in the treatment of Autism Spectrum Disorders.

Due to culture bound child rearing practices, caregivers may not feel comfortable incorporating the recommendations of a mental health specialist (Trembath, Balandin, & Rossi, 2005). In the Midwestern United States, Jegatheesan, Fowler, and Miller (2010) interviewed six biological parents, from three families of South Asian decent, living with a young ASD child. Interviews were conducted in the caregivers' native tongue (Hindi, Urdu and Arabic) focusing on their reactions to the diagnosis, understanding of etiology, treatment, process of obtaining services and experiences with professionals. The interviews revealed cultural reasons for a delay in diagnosis. When caregivers raised concern about their child's loss of language, family and community members explained

that “boys speak later than girls” (Jegatheesan et al., 2010, p. 803) so that there was no reason to worry. Post diagnosis, members of the family and community sought to understand how the mother had “damaged the child’s brain” (Jegatheesan et al., 2010, p.804) prenatally, pointing to superstitious beliefs about improper diet and evil omens. Parents cited their frustration with mental health professionals’ use of jargon and their perception that the professional did not involve elders living in the home as collaborators in establishing treatment goals for the child.

In general, expectations of caregivers can vary greatly. It can range from expecting their child to be cured of all associated ASD symptoms and others for their child to require lifelong assistance and to live in a residential mental health facility. Culturally based interpretations of how one is expected to contribute to the greater society can also affect caregiver expectation (Wilder et al., 2004). For example, some families may believe that the individual with ASD will spend the entirety of their life in the family home versus holding a job in the community. To complicate matters of caregiver expectations, there is a phenomenon referred to as the “cure of the month.” These cures are new and not yet validated treatments that frequently promise to eradicate symptoms associated with Autism (Offitt, 2008). These treatments can be costly and sometimes dangerous but tend to appear more appealing than daily behavioral tutoring, which sometimes produces slower or less dramatic progress. This can overwhelm and frustrate caregivers who do not want to feel as though they have given up hope for their child’s outcome.

There also exists a group of individuals who proudly identify themselves as being Autistic or being “Aspie,” diagnosed with Asperger’s Disorder. There is a culture of

disability in which some people identify strongly with their diagnostic label. They are proud to be identified as being “Aspie” and refer to other non-ASD people as “neurotypicals. It is important for paraprofessionals to understand that people who are proud of their identity as it relates to these diagnosis, can sometimes feel insulted when presented with advocacy efforts focused on curing their Autism as if were an ailment. These groups have also voiced their frustration over the proposed DSM diagnostic change in which Asperger’s Disorder will be subsumed into the Autism spectrum as opposed to being a separate diagnosis.

### **Home Based Service Delivery**

Empirically supported treatment of ASD symptoms involves early intervention, which can begin when a child is as young as 2 years of age. The home-based ABA program involves paraprofessional behavioral tutors spending sometimes 30-40 hours in the client’s home engaged in intense behavioral tutoring. Grindle, Kovshoff, Hastings, and Remington (2009) interviewed 53 parents whose Autistic children had received at least 2 years of ABA tutoring for up to 40 hours per week. They found that although parents supported ABA as being helpful for their child and family, that this home-based treatment presented several challenges. Families cited their struggle to fund the program whether it consisted of acquiring funding through their local educational system, regional center or by funding it themselves (using the child’s college savings, their own savings, mortgaging their home) as being of concern. Caregivers also cited a variety of difficulties with working with the behavioral tutors whom conducted tutoring within their home. Some of the problems stemmed from a lack of professionalism (last minute cancellations,

frequent tardiness, poor interpersonal boundaries), high turnover of tutors, as well as the discomfort of having numerous people in one's home on a regular basis.

#### **Chapter 4: Culturally Responsive Preparation for Professionals Treating Autism Spectrum Disorders**

Although there is a lack of research on multicultural issues in autism, Wilder et al., (2004) proposed culture specific strategies for meeting the treatment needs of individuals with autism in a culturally responsive manner. They explain that, "If the intention is to prepare professionals to be able to truly serve students with autism, efforts must be made to produce culturally responsive education programs" (Wilder et al., 2004, p. 109). Of paramount importance is having respect for the client and the client's family with whom they work.

In describing the ideal ABA tutor who behaves multi-culturally and develops multicultural curricula, investigators suggested that these individuals have a deep level of understanding and respect for their own cultural heritage. With the ability to understand and accept one's own belief system, the tutor can begin to acquire the knowledge and skills by which to be equip to work with individuals from cultures different from their own and as a result be able to better serve the mainstream culture. Wilder et al., (2004) explain that the characteristics of a culturally sensitive tutor include a curiosity for learning about customs, communication styles, mores and belief systems of different cultural groups. They stress that professionals preparing to work with this population must not accept a deficit orientation, but instead they must know how to empower the client and caregivers by way of building upon their strengths. Behavioral tutors must

keep in mind that their client and their respective family are resilient, capable, and motivated to improve their level of functioning.

### **Key Concepts**

1. Diagnostic profile-Triad of impairment: 1. 2. 3. There is a great deal of variation in the expression of the symptoms however social impairment is the key differentiating symptom from other childhood diagnosis
2. Treatment-the empirically supported treatment is behavioral therapy focused on decreasing behaviors disruptive to development and increasing skills that may be lacking as compared to children of the same age.
3. Outcome-ABA is not a cure for Autism Spectrum Disorders but rather is used to improve distress caused by symptoms associated with Autism.
4. Critiquing new therapies-since a variety of new treatment approaches frequently emerge, they may not have been scientifically tested and therefore may not be effective or safe. It is important that caregivers and behavioral tutors understand that questioning and critiquing new treatments is their responsibility to ensure the safety of the child.

### **Practice Topics**

Pair up and role-play ABA (and remember, you don't have to be a docile "client")

- Teach object labels/matching using different language or made up words
- Come up with as multiple ways to teach prepositions

## **Module 2**

### **Cultural Competence**

#### **Chapter 5: Introduction to Cultural Issues in Home Based ABA Treatment**

Although behavioral approaches can be theorized as being culture free, home-based treatment presents a host of issues that paraprofessionals must be prepared to encounter. As stated earlier, a client's home may expose an ABA tutor to a plethora of factors that they may not have expected to be a part of their job. Standard training of ABA tutors can include the basic principles of behavioral therapy as well as scientific support for the behavioral treatment approach. As noted in the previous training module, this job is not as simple as walking into a house, sitting with a child, and beginning a pre-prepared behavioral program. Paraprofessional tutors will find themselves exposed to the clients' lifestyles, the resources available to them, their religious and political affiliations, and possible family chaos and/or marital discord (Schacht et al., 1989). Behavioral tutors can become an important source of information for the family. With so many factors at play, the tutor will need to be able to tolerate experiencing moments when they are not in complete control of the therapy environment (Schacht et al., 1989). Even in this changeable situation, ABA tutors are expected to be able to perform their job in a culturally responsive and professional manner that exudes respect for the client and family, fostering a healthy working relationship.

## **Cultural Competence**

Mental health specialists are ethically responsible for delivering culturally competent support to their clients. This requires clinicians to attain a level of appreciation for their clients' value systems, beliefs, and customs. According to LaFromboise, Coleman, and Gerton (1993), if one assumes that culture is shaped and influenced by one's cognitions and responses in a particular social environment, to achieve cultural competence, one must:

(a) possess a strong personal identity, (b) have knowledge of and facility with the beliefs and values of the culture, (c) display sensitivity to the affective processes of the culture, (d) communicate clearly in the language of the given cultural group, (e) perform socially sanctioned behavior, (f) maintain active social relations within the cultural group, and (g) negotiate the institutional structures of that culture. (p. 396)

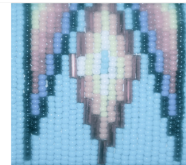
Without expending the effort to improve one's understanding of a client's cultural context, therapeutic goals such as establishing rapport with the client and even simple communication can be thwarted through misunderstanding. Still worse, the client may experience the clinician as being naïve or disrespectful. In this case there is the perception that the treatment being delivered is destructive with regard to the client's cultural beliefs (Jackson & Hodge, 2010; LaFromboise & Rowe, 1983; Yukovich & Lattergrass, 2008). Research supports that providing culturally appropriate services can improve attrition and treatment outcome (Hays, 2009; Jackson & Hodge, 2010; LaFromboise & Rowe, 1983).

As there are countless possible variations of beliefs and values across cultures this is further complicated by the varying degree of acculturation within the individual's dominant culture. Professionals must first examine their own beliefs and values before building a skill set to work with an individual who identifies with a different culture.



Achieving cultural competency requires an ongoing desire to deeply understand the nuances of culture. Such exploration covers many domains and the process of acquiring such skills can be life-long (LaFromboise et al., 1993). A single course on the subject in a clinician's training could not be sufficient to cover such self-examination and careful regard for another (Rogers-Sirin & Sirin, 2009). One must commit to ongoing self-assessment and a genuine interest in the deeper understanding others to accomplish this ability.

## Cultural competence



Coleman, Gerton, and La Fromboise, (1993, p. 396)

Culture is shaped and influenced by one's cognitions and responses in a particular social environment, to achieve cultural competence, one must:

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- b) have knowledge of and facility with the beliefs and values of the culture,
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- e) perform socially sanctioned behavior,
- f) maintain active social relations within the cultural group, and
- g) negotiate the institutional structures of that culture.

### **Acculturation**

Following prolonged contact with a majority culture Individuals belonging to marginalized ethnic groups begin to adopt the beliefs, customs and values of the dominant governing society (LaFromboise et al., 1993). Acculturation can be defined as the level or degree to which the majority culture has been internalized and adopted by the individual from a marginalized ethnic community. Unfortunately acculturation can be accompanied by a need to conform to the dominant culture with the implication that the marginalized culture is deemed to be inferior or less important. This sort of thinking supports prejudice and discrimination against the marginalized group (LaFromboise et al., 1993). One indication of the level of acculturation is the loss of one's mother tongue in place of the governing cultures language. Other factors include the number of generations since an individual's family lineage had their first contact with the majority culture and/or status of one's citizenship within the dominant culture. Sometimes majority beliefs are adopted whole-heartedly and at other times they are slightly modified to incorporate remnants of the marginalized individual's culture of origin. Although the individual will always be considered to belong to their original cultural group, that individual will be a functioning member of the majority culture.

### **Bicultural Competence**

Bicultural competence refers to instances in which an individual is capable of successfully navigating social situations involving two different cultures. One must be able to present appropriate social behavior and decorum while maintaining equal respect for both cultures. Not only does bicultural competence involve having an accurate

understanding of the two relevant cultures, but also it includes the ability to discriminate when it is appropriate to invoke specific behaviors expected in the proper context (LaFromboise & Rowe, 1983). There can be a variety of circumstances which lead an individual to adopt a more bicultural set of beliefs. Native Americans are indigenous to North America, in contrast to immigrants to the United States; therefore, their existence is often described as straddling two worlds. They function in the world holding the beliefs established by their traditional Native American ancestors and that of the dominant post-colonial society. LaFromboise, Albright, and Harris (2010), found that Native American adolescents who possessed a greater sense of adeptness in both the Native American and Western culture expressed less hopelessness than those with greater identification with only one of the cultures.

## **Chapter 6: Cultural Guidelines**

It can be common practice in the United States to refer to individuals who conduct behavioral services to children with ASD as “behavior therapist” despite the fact that they are not trained or licensed psychotherapists. While conducting in-home tutoring, paraprofessionals are bestowed the caregivers trust and respect as a professional. With this respect comes great responsibility. It is the goal of this training resource to equip paraprofessional tutors with the tools needed to perform their duties professionally allowing them to enjoy their work and use their creativity in exploring new ways to introduce and teach concepts to their client.

As a fledgling ABA tutor, the author recalls trying in earnest to provide the best teaching to ASD clients without the understanding of basic codes of conduct while

working with cultures different from one's own. That said every new client had to be approached like a new and complex mixture of cultures. The author had to keep in mind her own culture of origin; female, White Mountain Apache/Durango mountain Mexican, first generation college student raised in East Los Angeles with neighbors that are descendents of Japanese families forced to live in once local intern camps during World War 2. Taking pause to reflect upon the complex combination of elements that define one's own culture and level of acculturation can remind us that each new client can possess an equally if not more complex set of values and beliefs.

In order to provide the much-needed skills, I will paraphrase the "American Psychiatric Association (2011) Cultural Guidelines" which are presented as a guide to providing services to multicultural populations. Below you will find applicable guidelines translated for application in home-based ABA services:

1. The service provider should be able to explain the treatment goals and expected outcome. As the tutor is not a therapist, the rules of confidentiality should be respected, however there are no governing bodies or rules to enforce this rule. This is when one must consider the vulnerability of the client's caregivers. If individuals were allowed into your home on a daily basis, would you feel comfortable (i.e. trusting) these strangers in your home?
2. As a behavioral tutor, it is important to stay current on the latest information about ASD. This includes the latest treatment approaches as well as information available in the media.

3. One must be aware of the ways that one's own cultural background can affect treatment. One must also be cognizant of the ways in which the client and their caregivers may be discriminated against by society due to their cultural background.
4. ABA tutors must have respect for the client's family members and caregivers. They should also accept that the family structure of the client's family may differ from their own family structure.
5. Possess respect for spiritual and/or religious values of the families. As soon as one is aware of cultural beliefs and values that their client identifies with, the behavioral tutors should take it upon themselves to learn basic tenets of those beliefs. Education should involve special attention to taboo behaviors that can be avoided so as not to inadvertently offend the client and their caregivers.
6. One should be considerate of the client's family when they make requests to teach a client in their language of origin. Translators should be used if necessary during regular supervision meetings attended by the behavioral team and family.
7. Important information about the client and their family which can improve rapport, increase the cultural relevance and efficacy of treatment can be derived from the following questions:
  - a. How many generations has the individual lived in the U.S.? Are there multiple generations living in the home?
  - b. If the client comes from outside of the U.S., how long have they lived in the country? Have they moved frequently? Has their status changed as a

result of coming to this country? Do they have concerns over immigration status?

- c. How fluent are caregivers in English? Is a translator necessary when working with the family or otherwise sharing information?
- d. Does extended family offer support? Who else or what other resources are available to support the family?
- e. What support is found or not found within the community?
- f. What is the level of formal or informal education?
- g. Does the process of acculturation bring the family additional stress?

**Key Concepts**

Cultural competence as explained by LaFromboise, Coleman, and Gerton, (1993):

1. possessing a strong personal identity,
2. having knowledge of and facility with the beliefs and values of the culture,
3. displaying sensitivity to the affective processes of the culture,
4. communicating clearly in the language of the given cultural group,
5. performing socially sanctioned behavior for the cultural group,
6. maintaining ongoing social relations within the cultural group, and
7. negotiating the institutional structures of that culture. (p. 396)

**Practice Topics**

- Where does your cultural competence lie? What elements of culture do you possess?
- Have you even experienced cultural discrimination? Disrespect of your belief or values?
- What areas do you feel you need more education on working with a culture, which differs from your own to better prepare you?

### **Module 3**

#### **Native American Families**

##### **Chapter 7: Working in Native American Homes**

There can be many pitfalls an ABA tutor can encounter if they have not been educated on the client's cultural heritage, beliefs and values. This is of paramount importance when working with Native American families. Current understanding of Native Americans by non-native Westerners can include the stereotype of the stoic, brave warrior immersed in beliefs about the world that mimic New Age beliefs. The stereotype can be negative, related to the high incidence of substance and physical abuse, violence and suicide supported by U.S. census data. The ABA tutor must enter the Native American home with respect and knowledge about societal and cultural factors that can directly affect the efficacy of their work in order to develop a professional working relationship with the client's family.

##### **Factors Related to Under Utilization of Health Services**

To understand the current state of the relationship between government services and the Native American people, it is important to refer to the tragic history with the services established by the early colonizers. As a result of broken treaties and treatment which was intended to strip the Native Americans of every aspect of their culture, many Native Americans continue to harbor a great deal of distrust for the laws and governmental boundaries enforced by the early colonizers (Bee & Gingerich, 1977). This very same distrust has been transferred over to other institutions including those that



provide mental health treatment. Mental health services tend to be underutilized by the Native American population despite the fact that according to the *Diagnostic and Statistical Manual*, the rates of the occurrence of mental health illness within the Native American population is comparable to the general American population (Bichsel & Mallinckrodt, 2001).

Access to mental health services for Native Americans have improved with the organization of Indian Health Services along with the organization and recruitment of Native American mental health providers; however, these services continue to be underutilized. Determining which healthcare system is used is sometimes dependent on whether a family lives closer to and has access to Indian Health Services or mainstream health care centers. A family living on more rural tribal land may have to travel great distances at great expense to obtain mental health services. Another complication is that the federal government does not recognize all tribes as sovereign nations. This means that unrecognized tribes are not considered independent from the U.S. government therefore, they are not permitted to govern themselves out of the jurisdiction of U.S. law and are ineligible for aid through Indian Health Services as well as U.S. social services.

## **Chapter 8: Introduction to Native American and Inter-tribal Variation**

There is great variation across tribes and clans of the people indigenous to North America. Not only is there great variation in language but also in customs and traditions. Currently people identifying as Native American live across the United States presenting major cultural differences dependent on whether they live in rural versus more urbanized locations. For those living in rural areas, there can be great variation among families

living on the reservation versus off. As one would expect, confidentiality concerns can be paramount in smaller rural areas. Gossip can travel fast in small communities. Access to support services and clinical team meetings can also be greatly affected by accessibility.

### **Native American Communities**

Indian societies have gone through dramatic changes during the past century; yet, there are people in rural areas who can be more rooted in cultural traditions and who hold on to knowledge, attitudes, and beliefs that are quite different from the majority American culture. “While diversity in language, customs, and traditions are typical across tribal societies the essence of traditional life is captured through important markers such as spirituality and relationship patterns among kin,” (Red Horse, 1997, p. 243).

The communities can consist of extended families that resist intrusions, especially by politically organized human services which can be interpreted as being designed to tamper with the sacred ways of traditional Native American life. Extended kin systems are related by blood, marriage, or adoption and are commonly referred to as family. They include vertical and horizontal dimensions. In Sioux tribes, people are talked about using words denoting relationships as opposed to names.

To traditional American Indian communities, development is a phenomenon whereby age and independence are negatively correlated. This assumes that Native American children should possess independence to explore and learn through their experience. As individuals become older they are expected to assume increased kinship responsibilities. Within western culture the belief is the opposite, children are dependent on their parents who discipline them and teach them about their world. Westernized

individuals are expected to become independent of their family of origin as they become older.

Traditional American Indian communities are known for tolerance of differences. They accept individuals who were on the margin and who in today's American society would be shunned. Prior to colonization some tribes did not have a word for developmental disabilities. Individual differences are incorporated into traditional societies through a context of spiritual definition. Thus, health characteristics that would be defined as disabilities in the language of America's human service professions were framed as special strengths in traditional Native American beliefs. It is important to note that, as with all groups, each Native American individual will vary in their degree of acculturation or socialization into the majority culture.

## **Chapter 9: Native American Traditional Values and Beliefs**

There are approximately 5.2 million individuals who describe themselves as Native American in the United States (U. S. Bureau of the Census, 2011). Out of this population, there are currently 336 federally recognized tribes that are eligible for funding through the United States Bureau of Indian Affairs. There exist about 250 known different languages and dialects (McCarty, 2008; U. S. Bureau of the Census, 2002). Within each of these tribes or bands, a variety of norms and mores exist. Each group possesses their own values as well as varying degrees of cultural identification and assimilation in to general American culture. Despite the diversity across tribes, the two important themes that emerge are the importance of familial relations and spirituality. For the purpose of this training resource, the general values of North American Native people

will be presented; however, it is important to stress that further research into individual customs would be necessary when a specific tribe is identified by a client.

### **Native American Worldview**

Traditional Native Americans possesses a relational worldview that emphasizes how all phenomena are interrelated. This view values harmony with the natural and spiritual worlds along with a philosophy emphasizing humility and sharing as opposed to competitiveness (McGoldrick et al., 2005; Red Horse, 1997). This philosophy values the act of placing community needs before individual needs (Guillory & Wolverton, 2008). A great deal of respect is bestowed on elders of the group who are responsible for leading and carrying out the traditional customs. There is a time orientation that favors living in the present. It is acknowledged that events will occur in their own time, that is, an event will end when it is finished and not according to a predetermined schedule. This view of time is in opposition to the mainstream view, in which being an agent of one's time, making actions happen at one's own will, and living toward the future are valued. As opposed to seeking scientific justification, a traditional Native American worldview favors understanding phenomena in terms of the supernatural. It is clear that there are many instances in which this worldview is at times in direct opposition to the Western world view which values freedom, physical health and enterprise.

### **Native American Families**

Native American's family relations are so important that, traditionally, when individuals meet for the first time, they describe themselves in terms of whose family

they belong to and where they come from. This relationship with one's family and ancestors is of utmost importance and is considered to be completely interrelated to all other forces of nature (Garrett & Garrett, 1994).

The concept of family relatedness extends to include other's relatedness to the tribe as well. Animals are referred to as "four-legged brothers and sisters", the earth as "our Mother", "Father Sky", "Grandmother Moon," and "Grandfather Sun" (Garrett & Garrett, 1994)." This emphasizes one's interrelatedness with the universe to be both biological and spiritual (Garrett & Garrett, 1994; Portman & Garret, 2006).

One of the strongest-held values by Native Americans across tribes and bands is that of the importance of family. Although there can be great diversity of beliefs across tribes such as those regarding family structure, for example, matriarchal versus patriarchal rule, the core value of the importance of family is universal in a traditional Native American household (Garrett & Garrett, 1994; Red Horse, 1997). Family is defined as one's blood relatives, which includes all extended family. When a traditional Native American refers to their family, they include grandparents, aunts, uncles, and cousins. However kinship is not limited by blood relatedness. Cousins are referred to as siblings and terminology does not exist to distinguish relations by marriage, such as in-laws; these individuals are simply considered to be a part of the family. Important members of the community can also be acquired into the family. This is especially true with reference to healers or medicine people. In other words, one's social or cultural relationship to the family can be the defining element in one's relatedness.

Native American families that choose to follow the traditional lifestyle of generations past favor grandparents as the primary caregivers of children (Bahr, 1994;

Mutchler, Baker, & Lee, 2007). Child rearing is the main responsibility of a child's grandparents, in contrast to Western standards, which places the responsibility on the birth parents (Herring, 1990). While grandparents watch over the children, more traditional Native American birth parents are responsible for all economic provisions (Garrett & Garrett, 1994). It is not uncommon for more traditional households to house both the nuclear and extended family (Guillory & Wolverton, 2008). An ABA tutor who is not aware of these alternative family roles and structure could have the impression that the birth parents of the client are negligent of the care for their children. Tutors may also undervalue the importance of including elder members in the behavioral program or may even fail to acknowledge them respectfully when entering the home. This kind of cultural violation can be deeply offensive to the family and result in decreased compliance or program support.

### **Native American Spirituality**

Traditional spiritual beliefs emphasize a circular relationship in which one must maintain harmony and balance within oneself as well as with nature and the spirit world to experience spiritual wellness. An emphasis is placed on making choices that benefit the greater community over choices that further independent wealth. The metaphor used to promote spiritual beliefs in harmony is the circle. The circularity of life is utilized in various ceremonies to emphasize that life is a cycle that continues and begins again. Behavior that one engages in now will affect many more generations to come.

The medicine wheel is a circle, which is divided into quadrants symbolizing the four sacred directions. The four directions, which are at times depicted in the colors red,

black, white, and yellow; symbolize the spiritual elements of fire, earth, water, and wind. The sacred elements are considered gifts bestowed by the creator that are to be respected. The quadrants are also used to symbolize the four dimensions of a person: (a) spiritual, (b) emotional, (c) physical, and (d) cognitive. Unlike the Western conceptualization of an interaction between one's mind and body, the Native American medicine wheel includes all four indivisible quadrants. One's spirituality and physical elements which are of equal importance to one's mind and body. Individual harmony can be achieved when one finds a balance among their emotional, spiritual, physical and mental health.

Yurkovich and Lattergrass (2008) conducted a study which examined how "good health" versus poor health is defined by Native Americans suffering from persistent mental illnesses. Participants described an unhealthy state as one in which a person loses the ability to keep the four quadrants balanced. When an individual experiences active mental illness, they have an imbalance of harmony; that is, they are experiencing suicidal ideation (cognitive), depression, or feelings of rage (emotion), loss of hope in one's support (spiritual) and poor health due to poor diet (physical; Portman & Garrett, 2006). A healthy state is defined as equilibrium of the four domains of the medicine wheel (Portman & Garrett, 2006).

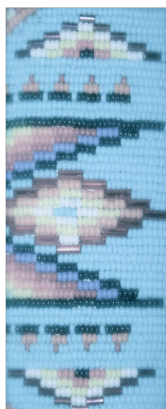
It is important to note that these aforementioned values are traditional Native American beliefs. Great variability exists amongst the population that identifies themselves as Native American. One's cultural beliefs are a synthesis of internal and external processes. One must take into account not only variation between tribes but also varying levels of acculturation of the client.

## **Chapter 10: Historical Trauma**

As one explores the historical context that shapes the current Native American collective experience, one cannot deny the impact of historical trauma. Similar to other oppressed or colonized indigenous people, contemporary Native Americans are survivors of genocide and intergenerational trauma (Duran, Firehammer, & Gonzalez, 2008). It cannot be denied that a tragic history of damaging emotional experiences have been passed down through successive generations of Native American descendants. Traumatic events resulting from the genocide or the result of being raised by abused caregivers, who face their own struggle to recover from their own trauma experiences. The history of abuse is exacerbated and continued as supported by high rates of domestic abuse, substance abuse, lack of resources, money, food, and/or education in Indian country. As a culture, Native Americans possess many adaptive coping practices and ceremonies utilized to deal with traumatic experiences. Many of these practices were outlawed during the early colonizer's attempt to "civilize" the indigenous people, at a time when they needed it the most. Native Americans were not allowed the time to heal before incurring subsequent trauma experiences.



## Historical Trauma



### Timeline of U.S. government involvement with Native Americans

- **1785 Hopewell Treaty** – required that Cherokee, Chickasaw, and Choctaw tribes allot land for white settlement
- **1819 Civilization Fund Act** – provided grants to private agencies to establish programs to “civilize” or assimilate NAs
- **1830 Indian Removal Act** – authorized president (Hoover) to make treaties to exchange NA land east of the Mississippi River for land west of the river
- **1857 NAs were “free and independent people”** who could become U.S. citizens
- **1884 “Placing out” system** – relocated NA children on farms in the east and Midwest so they could learn the “values of work and the benefits of civilization”
- **1924 Indian Citizenship Act** – granted U.S. citizenship to all NAs
- **1959 Indian Adoption Project** - The Child Welfare League of America, in cooperation with the Bureau of Indian Affairs, 395 children placed with non-NAs
- **1975 Indian Self-Determination and Education Assistance Act** – encouraged self-government among NAs. 562 federally recognized tribal governments in the United States could create their own government, enforce civil and criminal laws, tax, and devise requirements for membership
- **1976** - a study conducted by the Association on American Indian Affairs found 25-35% of all NA children were placed in out-of-home care and 85% of those were placed in non-NA homes or institutions
- **1978 Indian Child Welfare Act (ICWA)**-requirements for child placing agencies, culturally appropriate services, notifying tribes, requires children be placed in NA homes, NA tribes to reassume jurisdiction over child welfare matters, developing & implementing juvenile codes, juvenile courts, tribal standards, and child welfare services

## **Boarding Schools**

After the American Civil War (1861-1865) and Indian wars (1811-1890), one of the federal programs, designed to “civilize the Indian,” implemented the use of American Indian boarding schools. In 1819 the U.S. government created the Civilization Fund Boarding Schools, which were large militaristic or mission schools for American Indian children three to 13 years old. These schools were sometimes referred to as the “Indian School Experiment.” Many of the schools were gravely overcrowded; some were reported to house more than 1,000 students. The federal education system was given the responsibility of taking on what was commonly referred to by early colonizers as the “Indian problem,” a term meant to refer to the process of assimilating the indigenous people to the more Eurocentric way of life followed by the early colonizers. The belief was that this education would require the removal of Native American children from their families and communities so that they could be prepared for “citizenship and all the rights and responsibilities appurtenant to it” (Dejong, 2007, p.257).

The use of boarding schools enabled colonizers to assimilate the Native American children into their own mainstream society. In an attempt to extricate their “savage” way of life Native American children were required to wear European style clothing, speak only English, and receive European style haircuts in order to receive food and housing (Dejong, 2007). Use of their indigenous language was grounds for sometimes severe punishment. Many of the schools belonged to religious organizations that also required the children to conform to their religious practices while using punishment or restriction from resources or other freedoms if the children were caught performing Native American ceremonies. Unfortunately, for the Native American children and their

families, these schools became increasingly oppressive, even making it illegal for Native Americans to use their native language in a federal school. Several hours a day children were required to perform manual labor in dangerous and unhealthy conditions under the conviction that this would prepare them for the kinds of jobs they were capable of performing as adults.

During the boarding schools' inception, Native American caregivers were reluctant to send their children to Indian boarding schools as they were known for having a high rate of mortality. According to Dejong (2007), students attending Indian boarding schools experienced double or triple the national rates for contracting smallpox, measles, trachoma, chicken pox, tuberculosis, and the mumps. At the Fort Apache Indian School dormitory, in order to prevent students from escaping the school, the windows were nailed shut, preventing ventilation in the dormitory where students slept three to a single bed. This environment mixed healthy with infected children increasing the spread of infection. One example cited that eleven out of 15 Shoshone boys died after they were sent to the Carlisle Indian School, located on a deserted military base in Pennsylvania. It was not uncommon for infected children to be sent home before they passed away, thereby increasing the likelihood of infecting the rest of their families and community of origin (Dejong, 2007).

In 1910, boarding school workers were granted bonuses for taking a leave of absence with the sole purpose of forcibly collecting as many Native American children as possible from the surrounding reservations by whatever means necessary. The Virginia Company authorized and offered cash rewards for the kidnapping of Native American children with the goal of "civilizing" Native American populations through Christianity.

Even in 2011, many Native American descendants recall being told by their elders to “just run as fast as you can” when an unfamiliar person approaches the reservation for fear that they would be kidnapped and taken to an Indian Boarding School. At Native American mental health trainings it is not uncommon to hear stories about boarding school in which individuals were beaten, humiliated or raped by staff. Following the 100 years of contact that the Native Americans have had with the early European immigrants, the collective experience including large scale massacres, broken treaties and boarding schools, give good reason for suspicion of (both) mainstream Euro-American services, as well as Indian-controlled ones (Guillory & Wolverton, 2008).

### **Intergenerational Trauma**

The sordid Native American history has contributed to skyrocketing statistics of abuse and mental health issues. Native Americans are overrepresented among the homeless (8%) and among individuals with drug and alcohol problems (as high as 70%) according to the 1999 U.S. Department of Health and Human Services Surgeon General’s Report. Among Native Americans between the ages of 15 to 34, they are 2.2 times more likely to commit suicide than the national average for this age group; suicide is the second leading cause of death for Native Americans. American Indian families are likely to have been exposed to violence, domestic abuse, suicide, health problems, substance abuse, and the stress of living in two worlds (traditional versus that of the dominant society) in substandard conditions. Their rate of violent victimization reported by the Department of Health is more than two times the national average and a 22% rate of exposure to traumatic events compared to 8% in the general population in the United

States. Brave Heart (1998) defined this cycle of historical trauma as, cumulative, collective emotional and psychological wounding. Events such as the past genocidal intent, forced removal of children, abuses sustained in boarding schools, are pervasive and are passed on across generations through continue cycles of violence and depression (Brave Heart, 1998).

### **Healing in Native American Communities**

Many Native American communities are experiencing a revitalization of traditional customs and beliefs. These beliefs are being used to strengthen and heal the community (LaFromboise & Rowe, 1983). The circle divided into the four sacred relational elements symbolizing the importance of keeping in balance have been modified to be used in the treatment of substance abuse and to develop a conceptualization of cognitive behavioral therapy (Coyhis & Simonelli, 2005). According to Duran, Firehammer and Gonzalez (2008), a history of trauma and the trauma that has been subsequently passed on through generations of survivors has created a “soul wound.” This pervasive wounding can only be transcended through the process of “soul healing.” Duran et al. (2008) explains that by taking a new perspective on the wounds of the past, a discourse can emerge that will allow for a better understanding of the past. This allows individuals to clear the way and move forward, breaking the cycle of “soul wounding.” He notes that these survivors can begin to question where they themselves learned their destructive behavior. The answer will typically lead them back to the individuals who raised them as children. The survivor is then asked about how or where their caretakers learned their own destructive behavior. Revitalization of traditional customs along with

this new narrative or way of considering their past can be the beginning of their “soul healing” process. Duran et al., (2008), state that in Indian country, being a well-meaning counselor is not enough to enable “soul healing.” A combination of cultural competence and psychological liberation, accomplished through self-examination and continuous deconstruction of the injustice that occurred in Native American history, will facilitate this process (Duran et al., 2008). As behavioral tutors it is important to understand this process so that the healing process is allowed to continue and not hindered by our involvement in their family.

### **Considerations for Home Based Treatment of Autism**

A family already burdened with historical as well as current life stress is pushed to the limits when their child is diagnosed with a pervasive developmental disorder such as autism. This diagnosis brings with it the added stress associated with having to work with and navigate through a variety of mental health, medical, educational, and at times, legal agencies, all of which are likely to hail from a different racial and cultural background.

A major barrier to culturally responsive treatment of Native American clients, stems from the fact that most mental health providers possess a more Western/European worldview. There also exists a myopic view of Native American mental health that simply focuses on dysfunction as opposed to the many strengths intrinsic to their culture. The concept of finding balance in one’s life through use of the four sacred directions of nature, spirituality, community, and the environment can be used to support and rebuild Native American families in need (Coyhis & Simonelli, 2005; Portman & Garrett, 2006).

Within the Native American community, efforts are being made to strengthen and revitalize the strengths inherent in traditional customs and beliefs.

### **Chapter 11: Closing Remarks**

Experience of historical trauma is not limited to Native Americans. Unfortunately oppressive rule and systematic genocide have left many marginalized groups of people struggling with the task of healing their community after generations of trauma. As the Native American community taps into traditional beliefs to find strength and resiliency, it is important for ABA tutors and mental health specialists to respect their healing journey. According to Duran et al., (2008), the healing process can begin when individuals honestly and openly address the tragic history of these marginalized people. Duran et al. theorize that by truly acknowledging this history, a dialogue can begin allowing for the cultural “soul healing” to occur. Native American communities can gain back their strengths and cultural identities liberating them from the cycle of self-destruction and in turn releasing the oppressor.

**Key Concepts**

1. This training is only an introduction to very generalized information about Native American beliefs and history. There is great variation in languages and ceremonies amongst North American indigenous people.
2. Native American families can include cousins and non-blood related individuals in the community. These individuals will all be important in the ABA program. All should be treated with respect and may be interested in being involved in monthly clinic meetings to discuss the child's progress and program.
3. As a result of historical trauma, Native American communities are on a healing path. Some traditional beliefs can offer them great strength on this path and the ABA team should respect and support these efforts.

**Practice Topics**

- How does the traditional Native American worldview differ from a Western worldview?
- What are the ways in which historical trauma can affect ABA treatment in the home? How could health care providers be perceived?
- How can you prepare yourself for work with Native American families?
- When you encounter problems arising from possibly culturally derived issues, who or where can you turn to for guidance?



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